MULTIDEMENSIONALITY OF CAREGIVER BURDEN IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Kathryn Miller, MSW

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Education department of School Psychology

Chapel Hill
2020

Approved by:

Sandra Evarrs

Jessica Dykstra Steinbrenner

Rune J. Simeonsson

Christina Christopoulos

Steven Knotek

ABSTRACT

Kathryn Miller: Multidimensionality of Caregiver Burden in Parents of Children with Autism Spectrum Disorder
(Under the direction of Jessica Dykstra Steinbrenner and Sandra Evarrs)

Parents of children with autism spectrum disorder (ASD) experience a higher level of burden than parents of typically developing children and parents of children with other types of disabilities (Kring et al., 2008 and Vogan et al., 2014). The stress process model provides a theoretical framework for understanding the caregiving role. This study investigated family and child characteristics associated with caregiver burden among parents of children with ASD in high school, and how family empowerment is related to their experiences of burden as a possible mediator and moderator. Participants included 397 caregivers of children with ASD in high school in the United States, ranging in age from 13 – 20 years. For parents of children with one or more co-morbidities in addition to an ASD diagnosis, findings revealed statistically significant associations between a child's ASD symptom severity, the caregiver's familial relationship to the child (e.g., mother, father, or other), and all three subscales of the family empowerment scale (i.e., Family, Service System, and Community/Political subscales). Controlling for other factors in the regression analyses, one or more co-morbid diagnoses in children with ASD, and the Family and Service System subscales of the FES were found to predict caregiver burden in parents of children with ASD. However, this study found no evidence of mediation or moderation of family empowerment on the three independent variables used in this study and

caregiver burden. Implications of findings are discussed with a focus on using the multidimensionality of caregiver burden.

ACKNOWLEDGEMENTS

I would like to acknowledge everyone who has played critical roles in my academic achievements and milestones. First, I'd like to thank my research advisor, Dr. Jessica Dykstra Steinbrenner, for her guidance and support on this project, and my dissertation chair, Dr. Sandra Evarrs, for always believing in me. I would also like to thank the members of my committee: Dr. Steve Knotek, Dr. Rune Simeonsson, and Dr. Christina Christopoulos, for agreeing to serve on my committee and for helping to guide my graduate studies as well as providing me feedback and continued support throughout the dissertation journey. In addition, I was fortunate to have individualized support at the Odum Institute for Research in Social Science, specifically, Nuvan Rathnayaka, who provided me with invaluable guidance that made statistical analyses and interpretation for this dissertation possible.

I would also like to take a moment to thank my loved ones and close friends. My wonderful parents, without them, this simply would have been impossible. I thank my father for his willingness to listen and guidance, and my mother for her inspiration and advice. To my friends, thank you for being there through many bouts of anxiety and always encouraging me, even when I wanted to give up completely. This exhausting and stressful journey would not have been as bearable without my, then colleagues, whom I started this journey with in 2014, who are now some of my closest and dearest friends. In addition, I would like to thank Elizabeth Gregory and Brad Ball for their willingness to provide my dog with a second home, where she is loved and provided for like one of their own, while I spent weekends working on dissertation.

Special thanks, to Eyes, Ears, Nose, and Paws (EENP) for always supporting me and providing me with adorable companions that enhanced my mental health throughout my doctoral journey, and especially during my brain abscess recovery in the hospital.

ACKNOWLEDGEMENT OF SOURCE

The research reported here was supported by the Institute of Education Sciences, U.S. Department of Education through Grant R324C120006 awarded to UNC-Chapel Hill. The opinions expressed represent those of the author and do not represent of the Institute of the U.S. Department of Education.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ABAS-II	Adaptive Behavior Assessment System-Second Edition
ABC	Adaptive Behavior Composite
ADDM	Autism and Developmental Disabilities Monitoring
ADHD	Attention Deficit-Hyperactivity Disorder
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CDC	Center for Disease Control & Prevention
CSESA	Center on Secondary Education for Students with ASD
DSM-III	Diagnostic and Statistical Manual of Mental Disorders, Third Edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
FES	Family Empowerment Scale
FPG	Frank Porter Graham Child Development Institute
IACC	Interagency Autism Coordinating Committee
ID	Intellectual Disability
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
IQ	Intelligence Quotient
IRB	Institutional Review Board
LEA	Lead Education Agency
Leiter-3	The Leiter International Performance Scale, Third Edition
NLTS-2	National Longitudinal Transition Study – 2

PDD	Pervasive Developmental Disorder
RRBs	Ritualistic and Restrictive Repetitive Behaviors
SRS-2	Social Responsiveness Scale, Second Edition, Teacher Form
U.S.	United States
Vineland-II	Vineland Adaptive Behavior Scales, Second Edition, Teacher
WJ-III ACH	Woodcock-Johnson Tests of Achievement, Third Edition
WJ-III COG	Woodcock-Johnson Tests of Cognitive Abilities, Third Edition
ZBI	Zarit Burden Interview

CHAPTER I: INTRODUCTION

The prevalence of autism spectrum disorder (ASD) has risen over the past several decades, and the Center for Disease Control & Prevention (CDC) report states that 1 in 59 children today are diagnosed with autism (Baio, 2014). ASD is a neurobiological developmental disability, first described by Kanner (1943), characterized by a range of social impairments, nonverbal and verbal communication difficulties, and excessive displays of restricted, repetitive, and stereotyped patterns of behavior (American Psychiatric Association [APA], 2013; National Institute of Neurological Disorders and Stroke, 2014).

The criteria for an ASD diagnosis have undergone significant changes as research has improved the definition and criteria for this disorder. The American Psychiatric Association (APA) first distinguished the clinical presentation of autism in 1980, with the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III). This publication provided diagnostic criteria for infantile autism and pervasive developmental disorder (PDD). The criteria and definition for autism has undergone multiple revisions and has since become recognized as a spectrum of behavioral characteristics, which results in varying degrees of functional limitations (Christensen et al., 2018). In 1994 the revised diagnostic criteria for ASD introduced five subtypes of autism, published in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). In the most recent publication of the Diagnostic and Statistical

Manual of Mental Disorders, Fifth Edition (DSM-5), published in 2013, ASD was redefined as a single disorder (Christensen, 2018). This definition of ASD, subsumed the previous categories of Asperger's disorder, PDD – not otherwise specified, and autistic disorder. More specifically, the DSM-5 provides two main criteria within this definition of ASD. Included in this diagnostic criterion for an ASD diagnosis are severity levels for social communication and restricted and repetitive behaviors (5th edition; APA, 2013). The three severity levels include level one requiring support and level three requiring substantial support. Further information about the diagnostic criteria for ASD is explained in the literature review.

Raising a child with ASD creates a variety of challenges for the family involved. For example, Shimabukuro, Grosse & Rice (2008) estimated that the median medical expenditure for individuals with ASD was approximately 8.4 to 9.5 times greater than individuals without an ASD diagnosis. In addition, the core characteristics that define ASD can cause disturbances in the family dynamics; and previous research has shown elevated levels of stress, anxiety, and depression in parents of children with ASD, as compared to parents of children with other developmental disabilities, such as Down Syndrome, attention deficit-hyperactivity disorder (ADHD), and Fragile X Syndrome (Pozo, 2011; Hartley, Seltzer, Head & Abbeduto, 2012; Dabrowska & Pisula, 2010; Smith & Anderson, 2014; Abbeduto et al., 2008). As the core symptoms of ASD continue into adolescence and adulthood and services often decrease when adolescents' transition out of the school system and into adulthood, much of the burden of care is placed upon the parents of children with ASD. Supporting the parents of children with ASD is important, especially as their children transition out of high school services into

adulthood. There is growing awareness regarding caregiver burden for families raising children with ASD (Smith & Anderson, 2014). Previous studies indicate parents of youth with ASD and parental stress were most strongly related to child's behavior and degree of conduct problems, rather than the severity of developmental delay, lack of adaptive skills, or demographic characteristics of the family (King et al., 1999; Hartley et al., 2012; Mao, 2012). Adolescents and young adults with ASD generally have continued impairment in communication skills, social interaction, and independent living skills as they age.

Given the crucial role that parents play in their child with ASD's life, and often acting as their main caregiver as they age, it is important that caregivers who provide for children with ASD receive support as their children transition out of high school. Additionally, it is important to recognize the factors that contribute to the burden that caregivers are facing as their children with ASD transition into adulthood, so the proper services can be made available to them to help alleviate some of the burden they may experience. As parents are usually the primary provider of care to their child with ASD, and often have other responsibilities to balance, this increase in care may lead to higher levels of stress in parents (Peer & Hillman, 2014). Moreover, having a child with disabilities is associated with child-caring stress as well as less time for parents to meet their own needs (Lee, Harrington, Louie & Newschaffer, 2008).

Although past research has focused on factors that contribute to caregiver burden in parents of children with ASD, much of the research used relatively small, homogenous samples. The research on parents of children with ASD has mixed results and does not examine a large array of variables that contribute to caregiver burden or use samples that reflect the diversity within the population of individuals with ASD. The current study

attempts to build on and address gaps in the past research by examining both child characteristics and family characteristics and how they contribute to caregiver burden. In addition, this study seeks to learn more about empowerment as a possible mediator or moderator of caregiver burden. There is a need for research on this topic to better understand factors that are related to caregiver burden that can contribute to the development of the proper supports for caregivers of children with ASD transitioning out of school services into adulthood. Additionally, it is helpful to identify the parents at greater risk for higher levels of caregiver burden, as those are the ones that targeted interventions may have the most robust results with.

Chapter II: REVIEW OF LITERATURE

Adolescents with ASD face an array of challenges as they prepare to transition out of high school often with less access to services, which can lead to increased levels of care provided by parents who are supporting them in this transition. Parents of children with ASD face unique stressors beyond the stressors of parenting a neurotypical child. This is in part due to the nature of ASD, as individuals with ASD are significantly impaired in social interaction/communication and show restricted and stereotyped patterns of behavior (APA, 2013). Previous research has shown parents of children with ASD report higher levels of stress and caregiver burden, as compared to parents of children with typically developing children, as well as children with other developmental disabilities, such as Down syndrome (Blacher & McIntyre, 2006 and Dabrowska & Pisula, 2010), ADHD (Cadman et al., 2012), and Fragile X syndrome (Hartley, Seltzer, Head & Abbeduto, 2012; Smith & Anderson, 2014; and Abbeduto et al., 2008). This review of literature will cover three main areas. The first component of the literature review will focus on the core features of ASD and their role in typical development which will give light as to why caring for children with ASD has unique stressors beyond the stressors of parenting a neurotypical child or typically developing child. The second component of the literature review will focus on conceptualizing the multidimensional concept of caregiver burden. This will include the theoretical framework of caregiver burden, in which two different models will be discussed and an emphasis will be placed

on the stress process model, which will be used as the theoretical framework for this study. The third section will focus on understanding current research in the literature about what may be contributing to higher levels of caregiver burden in parents of children with ASD. Following this review, the limitations of previous research and the rationale for this study will be discussed, including the research questions being examined in this study and related hypotheses to posed research questions.

Core Features of ASD

The DSM-5 outlines two main criteria to meet diagnostic criteria for a diagnosis of ASD. Individuals with ASD have core deficits in socio-communicative ability and behavior (Weiss et al., 2015). Deficits in socio-communicative ability or criterion A in the DSM-5, describe deficits in social-emotional reciprocity, nonverbal communicative behaviors, and developing and maintaining social friendships. Social-emotional reciprocity deficits, such as abnormal social approach and failure of natural back-and-forth conversation. Deficits in nonverbal communicative behaviors used for social interaction can manifest as poorly integrated verbal and nonverbal communication and lack of facial expressions and nonverbal communication. While deficits in developing, maintaining, and understanding relationships include difficulties adjusting behavior to suit various social contexts and absence of interest in peers (APA, 2013). Manifestations of Criterion A widely vary among those with ASD. Individuals with ASD may need assistance in navigating social relationships especially those that are more complex, such as employee/employer relationships or may engage in inappropriate social situations due to impaired recognition of nonverbal communication. Deficits in behavior to meet a diagnosis for ASD or criterion B, as defined by the DSM-5 describe ritualistic and

restrictive repetitive behaviors (RRBs). For children with ASD this can manifest in a variety of ways. For example, children with ASD may be highly sensitive to everyday stimuli when compared to typically developing children (e.g., the sound of a toilet flushing). This may also manifest in a diminished response to everyday stimuli (e.g., not noticing the changes in temperature) or may seem to derive excessive pleasure from certain stimuli (e.g., touching a particular texture; Kirby, White, and Baranek, 2015). Additionally, included in this category would be several types of RRBs, including but not limited to stereotypy, obsession, compulsions, echolalia, rituals, self-injurious behavior, and insistence on sameness (Malmberg, 2007). A diagnosis of ASD is determined based on DSM-5 criteria and other factors such as daily functioning and a thorough clinical interview with the child's caregiver and an assessment with the child.

In addition to the previous criteria being met for a diagnosis of ASD, individuals with ASD often have complex medical and psychological profiles with co-occurring medical or psychiatric conditions. For example, co-morbid medical or psychiatric conditions can include, but are not limited to anxiety, intellectual disability (ID), ADHD, behavioral, sleep, sensory processing, and gastrointestinal problems. Levy and colleagues (2010) reported that 83% of 8-year old children with ASD had at least one co-occurring developmental diagnosis, 16% had at least one co-occurring neurologic diagnosis, and 10% at least one psychiatric diagnosis in their secondary analysis of the data from the Autism and Developmental Disabilities Monitoring (ADDM) Network surveillance system collected during the 2010 survey year. Further, Boulet et al. (2009) found that 96% of children with ASD had one or more co-occurring developmental disabilities. In this study, a developmental disability was considered "chronic physical,

cognitive, speech or language, psychological or self-care conditions that typically originate during childhood; are likely to continue indefinitely; and require additional coordinated services, supports, or other assistance for an extended duration or during a lifetime" (pp. 19). For example, of the 79.5% of those with ASD, also had a co-occurring "other developmental delay," and 41.8% had a co-occurring diagnosis of ADHD (Boulet et al., 2009). Co-occurring conditions/symptoms can increase the societal impact of ASD, as they often contribute to a higher level of impairment and increased need for services (Soke et al., 2018).

As ASD symptoms persist into young adulthood, many of the impairments do as well. For example, many children with ASD show continued impairments in daily living skills, communication, social interaction, employment, and education (Cadman et al., 2012). Although these deficits continue into young adulthood, often there is less access and availability of services to support individuals with ASD into this transition into young adulthood. As ASD is a spectrum and presents differently among individuals diagnosed, there are several areas of an individual's life that are often impaired by a diagnosis that may need supports into young adulthood after high school. This support is often provided by the parents of those with ASD, which can lead to increased amount of stress and burden placed upon the parents. Furthermore, depending on the nature and severity of ASD symptomology, the individual may require significant personal care and monitoring to ensure their overall health and safety as they transition into adulthood and out of high school services. Much of this care is placed upon the parents of the individual, which can increase their stress levels (Peer & Hillman, 2014). Moreover, young adults with ASD and a comorbid ID will experience even more difficulty being

self-sufficient and living independently because of an inability to achieve a higher level of education and sustain employment (Mao, 2012).

Caregiver Burden

The concept of family burden has been widely discussed and is one of the most commonly used variables in caregiver research, however there is a lack of agreement on the conceptualization and concrete definition of caregiver burden. Caregiver burden is a multidimensional construct that maintains varying definitions within the literature. Moreover, the meaning of burden is further obscured by the use of other terms such as "well-being, stress, and adverse effects" (Montgomery, Stull & Borgatta, 1985). However, the concept of caregiver burden has been a useful way for researchers to conceive how the caregiving role may negatively impact family members who may take it on within their family. The concept of burden was first introduced in the literature by Grad and Sainsbury (1966) and was defined as any cost to the family of which the patient is a member. In 1980, Zarit and colleagues defined burden as "the extent to which caregivers perceived their emotional, physical health, social life, and financial status as a result of caring for their relative" (pp. 261). More recently, Vogan et al. (2014) describe caregiver burden as the "perception of psychological distress, anxiety, depression, demoralization, and generalized loss of freedom attributed directly to caregiving" (p.55). As the term caregiver burden is quite convoluted, it has been defined and conceptualized in a variety of ways in the literature, in large part because the concept of 'caregiver burden' is multidimensional (Chou et al., 2000). George and Gwyther (1986) defined 'caregiver burden' as encompassing the physical, psychological, emotional, social and financial stresses that individuals experience due to providing care. As there are many

dimensions of 'caregiver burden' according to this definition, research that investigates caregiver burden can include some or all of these dimensions. Furthermore, Pearlin et al. (1990) conceptualized caregiver burden as an outcome variable, when considered within the context of the stress process model. The stress process model incorporates multiple layers of stress (e.g., individual, family, and community level), with a focus on predicting mental health outcomes, while also accounting for possible mediators. By understanding how burden factors into the stress process model, researchers can gain greater insight into the variables that affect caregiver burden (Pearlin et al., 1990).

Theoretical framework. There are many theoretical models of stress in the literature, the double ABCX model and the stress process model seem particularly important in understanding the multidimensional factors of caregiver burden in parents of children with ASD in high school. A brief overview of the ABCX stress model will be followed by a discussion of the stress process model and its applicability to this study.

ABCX Formula. The ABCX Formula is the basis of most family stress models, based on research done by Reuben Hill, who is considered the father of family stress theory (Weber, 2011, p. 82). As a sociologist, Hill's research examined the ways that families managed stress during World War II. His model of the ABCX Formula focuses primarily on precrisis variables of families, with each letter of the formula signifying an element in the model (Weber, 2011 & McCubbin & Figley 1983). Much like a mathematical formula, a crisis-precipitating event or stressor A interacts with the family's crisis-meeting resources B, which interacts with the family's perception of the event C, and together they produce the crisis X. The ABCX model is used for analyzing stress and coping within families, however, it only describes precrisis variables and the crisis in

a linear, deterministic model (Weber, 2011, p. 84).

In 1983, family scientists Hamilton McCubbin and Joan Patterson, added postcrisis variables, into the ABCX Formula to create the Double ABCX Formula. The Double ABCX Formula explains and predicts how families recover from crisis and why some are better able to adapt than others to the ABCX Model (Weber, 2011, p. 83). Figure 1 shows a simple depiction of the Double ABCX Model. Within this model, stress is viewed as the interaction between demands (known as the stressors), on one hand, and available resources, coping style and cognitive appraisal, on the other (Stuart & McGrew, 2009). Although the Double ABCX model has been used successfully in several studies of adaptation of families of children with ASD, this dissertation uses the theoretical framework of the stress process model because it introduces the idea of a mediator variable that can provide additional information on the effects of the stressors on the outcome variable.

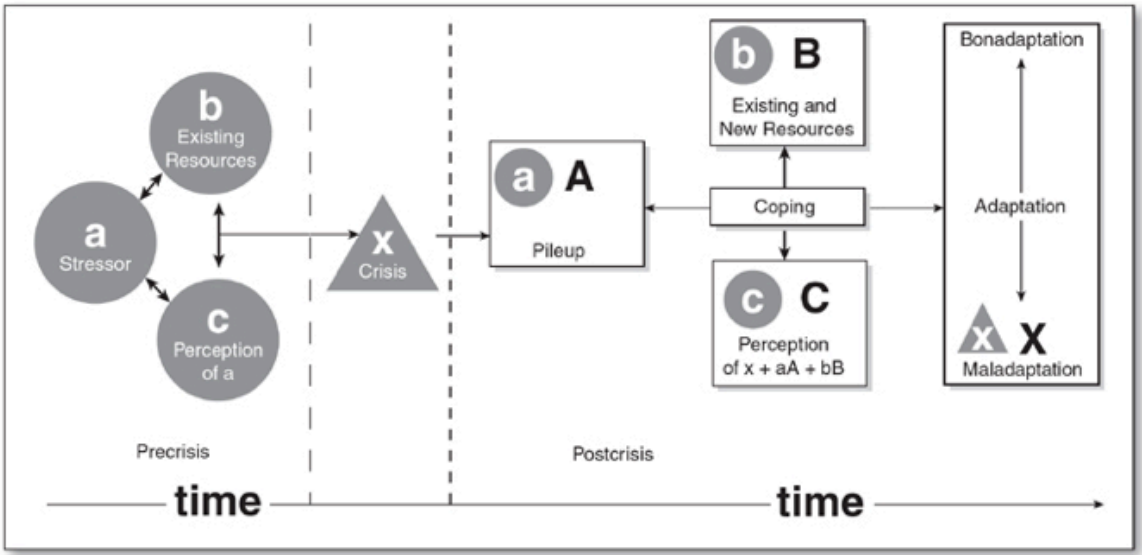

Figure 1. McCubbin & Patterson's Double ABCX Model.

Stress process model. Pearlin et al.'s (1981) research assessed the informal caregiving process, taking into account how life events, self-concepts, and social supports

come together to form a process of stress, using a three-dimensional concept of domains. These include, the sources of stress or the background and context of stress, the mediators of stress, which ultimately impacts the caregivers' wellbeing outcomes. Within each of these three domains (i.e., stressors, mediators, and outcomes) subsumes a variety of subparts. The caregiving experience and associated stress process reflects a process that changes over time. Moreover, Pearlin's stress process model suggests that primary stressors are those anchored in the needs and demands of the caregiving required, which interacts with secondary stressors, consisting of role strains and intrapsychic factors (intrapsychic strains involve dimensions of self-concept and kindred psychological states). Pearlin's stress process model suggests that stressors and resources (such as informational, emotional, and instrumental resources) exist which affect the caregivers' well-being, physical and mental health, and the caregivers' ability to sustain their own social roles (Pearlin et al., 1990; Raina et al., 2004). When applied to caregiving, caregiver burden is an outcome which is affected by the caregiver's background or the caregiving context, and primary stressors – which are those factors that are directly linked to the individual and the disability (Pearlin et al., 1990, Raina et al., 2004). This conceptualization allows for mediators to impact the caregiving role. It is critical to consider what variables can serve as mediators in relation to caregiver burden, to determine what can lessen the effect of the stressor (Raina et al., 2004). According to Hayes (2018), "the goal of mediation analysis is to establish the extent to which some putative causal variable, X, influences some outcome, Y through one or more mediator variables" (p. vii). Pearlin et al.'s (1990) conceptual model of caregiver stress was related to caring for a community dwelling individual with Alzheimer's disease can be

seen in Figure 2.

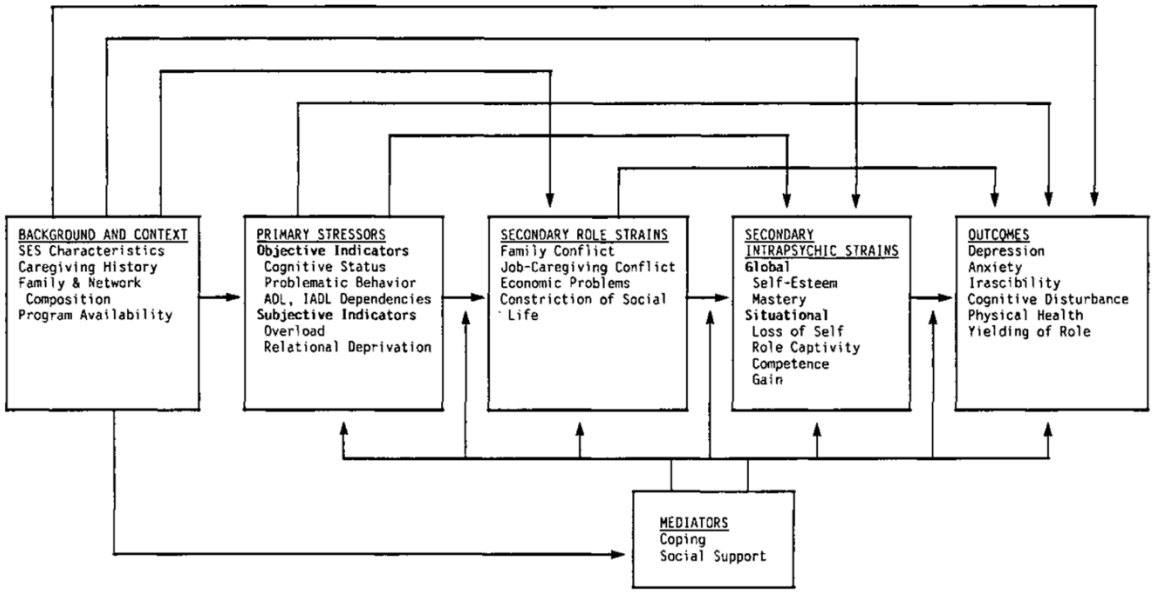

Figure 2. Pearlin et al.'s (1990) conceptual model of caregiver's stress relate to caring for an individual with Alzheimer's disease.

An adapted stress process model used for this current study is depicted in Figure 3. For the current study, background/context variables are considered family characteristics, such as the primary caregiver's educational attainment, total household income, the primary caregiver's relationship to the child with ASD, etc. Primary stressors are considered objective indicators of the child's level of functioning, such as cognitive abilities, adaptive skills, and ASD symptom severity, or other relevant child characteristics such as gender and age. Outcome within the context of this study is considered caregiver burden, and a possible mediator being considered is family empowerment.

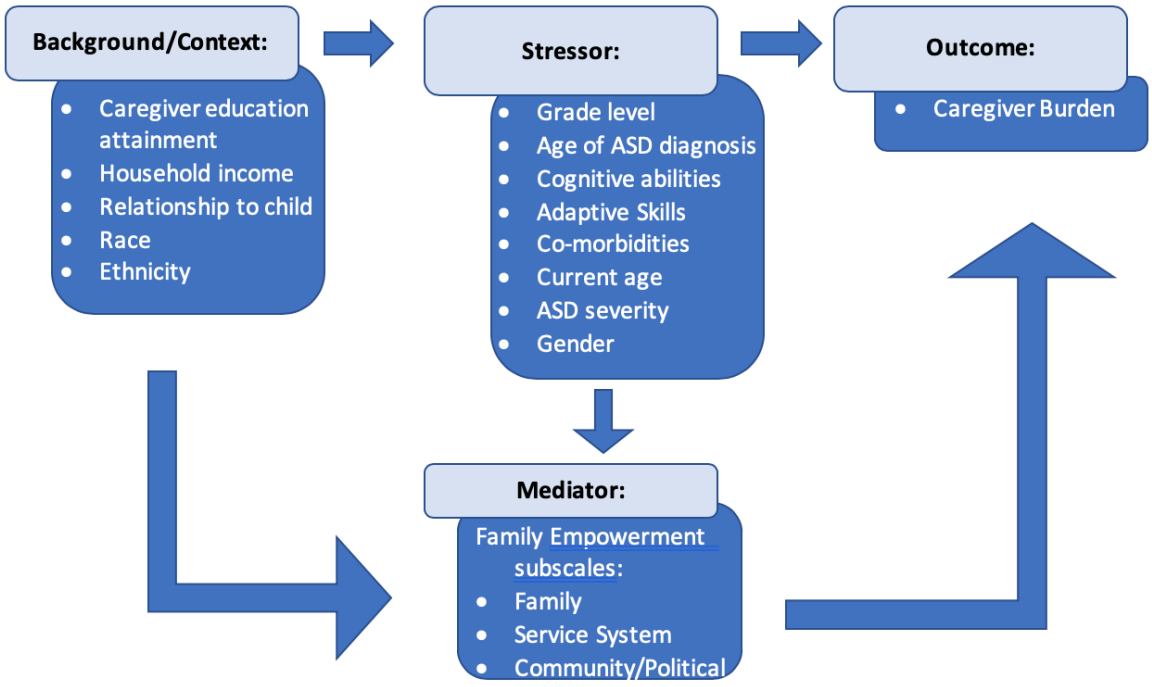

Figure 3. An adapted conceptual model of Pearlin's stress process model and the predicted relationships for this study (Pearlin et al., 1990).

Caregiver Burden in Parents of Adolescents with ASD

As ASD is a lifelong neurodevelopmental disability, mothers and fathers often have active parenting responsibilities in their child's adolescence and adulthood (Krauss, Steltzer, & Jacobson, 2005). Additionally, parenting an adolescent or adult with ASD presents unique challenges, including assisting the individual transitioning out of school services and navigating post-secondary education options, community settings, and long-term-care (Hartley et al., 2011). Families of children with ASD often have additional concerns that families of typically developing children generally do not have to consider. For example, parents with typically developing children can reasonably expect their children to gain independence around young adulthood in most cases. Parents of children with ASD do not have the same expectation, as care is often expected to continue throughout the lifespan (Cho & Kahng, 2015). Moreover, children with ASD require

additional time, preparation, thought, energy, and planning in terms of everyday activities that most parents of typically developing children take for granted, such as performing instrumental and basic activities of daily living and social outings (Harper et al., 2013). This can result in stresses and strains beyond those routinely endured by parents caring for only typically developing children. Whereas parents of typically developing children house, feed, clothe, transport, and financially support their offspring between 18 and 20 years, parents of children with ASD are engaged in care and provision of needs for their child often well into adulthood. Additionally, the transition out of high school for typically developing children is often a time of celebration and relatively smooth transition into post-secondary options such as schooling or job placements, however, for parents of children with ASD the transition is a time when preparations must be made for the transition out of school-based services into adulthood (Seltzer et al., 2003). Shattuck and colleagues (2012) found that children with ASD have poor postsecondary employment and education outcomes, especially in the first two years after high school, and often continue to live with their parents (Shattuck et al., 2012).

Outcomes for young adults with ASD. Two studies using the data from the National Longitudinal Transition Study – 2 (NLTS-2), a 10-year prospective study of youth receiving special education services conducted by SRI International for the US Department of Education, are important when looking at postsecondary outcomes for children with ASD as they transition into adulthood (Anderson et al., 2014 & Shattuck et al., 2012). The NLTS-2 used a stratified random sample of 3,634 Lead Education Agencies (LEAs) of the 12,000 LEAs that serve students receiving special education services in 7th through 12th grades. Students were selected randomly from each disability

category and sampling fractions were calculated to produce enough students in each disability category, and a total of 11,276 students were selected and eligible to participate in the NLTS-2. Data was collected in five waves, 2 years apart from 2001 to 2009. At the end of the study, participants had been out of school for up to 10 years (Anderson et al., 2014). The NLTS-2 uses the outdated term 'mental retardation' to be consistent with the federal special education category definition and to be consistent with how the data were collected, however it is noted that intellectual disability is currently the preferred term. Anderson et al. (2014) examined the prevalence and correlates of three living arrangements among a nationally representative sample of postsecondary young adults with ASD: with a parent or guardian, independently or with a roommate, or in a supervised setting. Using the data from NLTS-2 collected primarily in wave 5, collected from March 2009 to June 2009, Anderson et al. (2014) found that young adults with ASD (n= 620) were significantly more likely to have ever lived with a parent or guardian (87.1%) and less likely to have ever lived independently (16.6%) since leaving high school. Comparison groups for this study included mental retardation (n=450), learning disability (n=410), and emotional disturbances (n=380) (Anderson et al., 2014). Shattuck et al. (2012) examined prevalence of post-secondary education and employment among youth with an ASD, using a nationally representative survey of parents, guardians, and young adults with ASD and compared it to youth in three other eligibility categories. Using the data from the NLTS-2 collected in wave 4, from 2007 - 2008, Shattuck and colleagues (2012) found that compared to youth with a speech/language impairment (n=470), learning disability (n=460), and mental retardation (n=430), those with ASD (n=680) has significantly lower rates of employment and the highest overall rates of no

participation in employment or post-secondary education opportunities (Shattuck et al., 2012). Specifically, of the youth with ASD that had left high school within the last two years, more than 50% had no participation in employment or education. Additionally, Shattuck et al. (2012) found that higher income and higher functional ability were associated with higher adjusted odds of participation in postsecondary employment and education. Given that young adults with ASD have lower rates of postsecondary education and employment participation even compared to young adults with other disability types, it would make sense that this time would be a stressful time for parents of children with ASD. Moreover, this transition into adulthood for children with ASD is accompanied by a shift in service provision, as youth lose entitlement to school-based special education services and shift to a need-based model of service delivery, which can place an increased amount of care upon the parents of children with ASD (Anderson et al., 2014).

Previous research has linked a variety of child and family characteristics to caregiver burden in parents of children with ASD. An overview of the proposed factors that contribute to caregiver burden in parents of children with ASD is summarized below, along with the previous literature. Additional details regarding the demographics and features of the prominent studies on caregiver burden within parents of children with ASD can be found in Table 1.

Table 1.

Participant Demographic Characteristics by Study

Study	Diagnoses	n	Participant ages (years)	Location	Burden Measure
Vogan et al., 2014	ASD w/out ID ASD w/ ID	135 162	12 to 30	Canada	Caregiver Burden Scale - 9 items
Cadman et al., 2012	ASD ADHD	101 91	14 to 24	United Kingdom	Zarit Burden Interview- 12 Item
Kring et al., 2008	ASD only ASD w/comorbidities	130 142	10 to 52	United States	Burden Interview -29 item
Lin, 2011	ASD	50	10 to 18	Taiwan	Caregiver Burden Scale - 18 items

Child factors related to caregiver burden. A variety of child characteristics have been linked to caregiver burden in parents of children with ASD in the literature, including age of the child with ASD, adaptive functioning, cognitive functioning, the presence of psychiatric comorbidities in addition to an ASD diagnosis, and ASD symptom severity. The manifestation in the child's ASD symptoms and other characteristics of the child with ASD (e.g., cognitive functioning, adaptive functioning, academic ability, age) are objective conditions of the disability, and constitute actual care demands for the parent and would be considered stressors within the stress process model for this study (Raina et al., 2004).

Age. As children with ASD age out of the public-school system and pediatric health care system, much of the burden is placed upon their parents to find appropriate structured daytime activities, meaningful job and volunteer opportunities, and services to help with the individuals unmet needs, such as help with activities of daily living. Given these increased responsibilities that caregivers encounter when children with ASD

transition out of high school into adulthood, it is understandable that caregiver burden would also increase. Hartley and colleagues (2011) found that age was negatively related to parenting burden in their study of 91 married couples co-residing with their adolescent or adult with ASD, indicating that parents of individuals with ASD in the adolescent phase reported more burden than parents of adult children (Hartley et al., 2011). This finding contradicts previous research by Kring et al. (2008) that did not find that child age was a significant predictor of caregiver burden; however, this study was aimed at maternal well-being rather than burden. More recently, Vogan et al. (2014) found similar results, in that child age was not associated with caregiver burden in their study of 297 parents of children with ASD. Given that the research is mixed on whether or not the age of the child is associated with caregiver burden, more research on age is warranted.

Gender. As autism is four times more likely to occur in boys, according to the CDC, examining gender differences can be important in creating targeted interventions towards parents of children of specific genders (Christensen et al., 2012). There are a number of studies that have examined the associations between caregiver burden and gender differences, however, most of these studies use a more diverse sample of male to female ratio. For example, in Cadman et al.'s (2012) study, 92% of the ASD group were males, while in Vogan et al.'s study, 81.1% were male (Vogan et al., 2012). This is an important variable to examine in a larger more diverse sample (i.e., larger sample of females) to determine whether or not gender is associated with caregiver burden.

Adaptive functioning. The more adaptive skills an individual has attempted and mastered, the better he or she will fare as an adult in terms of employment, independent living, and overall quality of life (White et al., 2016). Individuals with lower adaptive

functioning would most likely depend on others, likely their primary caregivers, to support their engagement in activities of daily living (e.g., dressing and bathing). Weiss, Sullivan, and Diamond (2003) examined adaptive functioning of 97 individuals with developmental disabilities, aged 9.3 to 42.5 years as a predictor of parental stress, and found that lower levels of adaptive functioning were predictive of higher levels of parental stress. Similarly, Lin's study on caregiver burden in mothers of adolescents with an ASD in Taiwan found that caregiver burden is associated with less functional independence (Lin, 2011). Thus, it appears that adaptive functioning would contribute to caregiver burden, however this has not been studied in children with ASD in the US.

Cognitive abilities. According to a report by the CDC, among the children identified with ASD, approximately 32% of them also had an ID, which was defined as an intelligence quotient (IQ) score less than or equal to 70. In the same report, 44% of children identified with ASD had average or above average intellectual ability (CDC, 2016). One might assume that higher levels of cognitive abilities, lead to more skills mastered, which in turn leads to more independent living. Indeed, Vogan and colleagues (2014) found that the presence of a comorbid ID diagnosis was moderately correlated with burden in their study of 297 parents of individuals with ASD. It is important to consider that in their study parents were asked to indicate their child's level of cognitive ability and it was not directly assessed by validated measures of cognitive abilities. In contrast, Hartley et al. (2011) did not find this association with co-morbid ID, in their sample of 91 parents of children with ASD. Overall the evidence is mixed on whether lower levels of cognitive abilities contribute to higher levels of caregiver burden, thus more studies examining cognitive abilities in children with ASD in a larger and more

diverse sample is important in determining predictors of caregiver burden among parents of children with ASD.

Academic performance. The acquisition of functional academic skills can lead to better outcomes for children with disabilities by preparing children for employment, independent living, and economic self-sufficiency (Shandra & Hogan, 2009). Thus, one could presume that higher academic skills lead to more independence, which in turn can decrease the dependency that individuals with ASD have on their caregivers. It is important to determine if academic abilities are associated to level of caregiver burden to inform that the proper interventions can be created and put into place. The Woodcock-Johnson, Third Edition - Tests of Achievement (WJ-III ACH) is a useful assessment to measure academic performance and can be used as a stand-alone assessment to measure achievement in individuals (Wendling, Schrank, & Schmitt, 2007).

Age of ASD diagnosis. The American Academy of Pediatrics has proven that early treatment of children with ASD has shown to result in positive outcomes (Hyman et al., 2020). As an early diagnosis of ASD means obtaining and starting therapies sooner and can often lead to better developmental outcomes, it is important to examine if there is an association between the age of ASD diagnosis and reported levels of caregiver burden to determine if there should be a focus on earlier detection for ASD. There are few studies examining this relationship, however, in Lin's study of 50 children with ASD in Taiwan, they did not find any significant association between age of ASD diagnosis and caregiver burden. Looking at the relationship between the age of ASD diagnosis and caregiver burden of parents in the United States (U.S.) may help identify predictors of caregiver burden.

Grade level. Previous research has proven that parents of early adolescent children reported significantly more stress than parents of preadolescents or middle adolescents (Small, Eastman & Cornelius, 1988). Therefore, one would expect that as a child advances in school as well as in grade level, that caregiver burden would likely increase. In fact, Hartley et al. (2011) found that parenting burden was higher for parents with adolescent children with ASD than those with adults with ASD. In contrast, Lin (2011) did not find an association between child age and maternal well-being in their sample of 10-18-year-olds with ASD. Of note, these studies did not focus on grade level exclusively; thus, examining the relationship between grade and caregiver burden can help identify the timing of potential interventions to alleviate the burden caregivers experience.

Co-morbidities. ASD has been consistently linked to high rates of co-morbidities (psychiatric, medical, and behavioral), which could further contribute to caregiver burden and the need for parents continued support during the transition into adulthood. Prevalence rates of ASD and co-morbid conditions vary in the literature; Simonoff and colleagues (2008) noted that 70% of their 112, 10 to 14-year-olds had at least one co-morbidity (e.g., anxiety, oppositional defiant disorder, attention-deficit/hyperactivity disorder).

A number of studies have examined the association between caregiver burden and mental health problems, such as anxiety, bipolar, depression, and schizophrenia. Cadman et al. (2012) found that comorbid psychopathology significantly predicted burden in a study of 192 families with young adults, aged 14 to 24 (n=87 with ASD and n=86 with ADHD) in the United Kingdom. Additionally, Kring et al. (2008) found higher levels of

caregiver burden among individuals with ASD and psychiatric comorbidities as compared to those with ASD only. Based on these findings it appears that there is a relationship between the presence of a co-morbidity with ASD and caregiver burden.

ASD symptom severity. The severity of ASD symptoms is an important variable to capture in children with ASD, as many times it is one of the determining factors of the services an individual is eligible to receive (Weitlauf et al., 2014). As the core features of ASD (e.g., deficits in social communication and restricted and repetitive behaviors) can often lead to increased level of care, which is often provided by the caregiver, it is understandable that this is related to caregiver burden. In a large study of 880 parents of children with moderate and severe developmental delays, Smith, Oliver, and Innocenti (2001) found that the severity of the child's disability had minimal impact on paternal distress and that a child's social skills were a stronger predictor of parenting stress than were their motor, communication, adaptive behavior, or cognitive abilities. Further, Cadman and colleagues (2012) found that the severity of the ASD symptoms was not a significant predictor of burden in parents of children with ASD once need was controlled (need in this study was considered the caregiver's primary appraisal of care needs). In contrast, Kring et al. (2008), Lin (2011), Vogan et al. (2014), and Stuart & McGrew (2009) all found ASD symptom severity associated with caregiver burden. Of note, all of the aforementioned studies used different measures to assess the severity of ASD symptoms in their participants. Kring et al. (2008) used the Autism Diagnostic Interview-Revised; Cadman et al. (2012) used the Autism Quotient-Informant; Stuart & McGrew (2009) used the Gilliam Autism Rating Scale, Second Edition; Vogan et al. (2014) used the Social Communication Questionnaire- Lifetime Version; and Lin (2011)

based the severity of ASD diagnosis on a combination of verbal IQ scores, level of functional language, and social adaptation. Clear conclusions cannot be drawn based on the previous studies mentioned above, as most of them has small sample sizes of participants with ASD. A clear understanding of how ASD symptom severity is associated with caregiver burden, could lead to more effective transition services for parents of children with ASD or support services available to them.

Family characteristics related to caregiver burden. Currently, findings related to caregiver burden and family characteristics among individuals with ASD have been mixed; thus, further exploration into this area is warranted. Within the stress process model used as a theoretical framework for this study, family characteristics are considered background or contextual variables (e.g., respondent's relationship to the child with ASD, respondent's educational attainment, total household income) and can influence how stressors are experienced.

Respondent's relationship to child with ASD. Many of the previously mentioned studies either included exclusively mothers (e.g., Kring et al, 2008; Lin, 2011; and Abbeduto et al., 2004) or they included both mothers and fathers, but with majority response levels among mothers; thus, this variable is more exploratory in nature. It appears that burden is differentially experienced by men and women in the caregiving role because of persistent sex role differences and greater female life expectancy, women are much more likely than men to assume responsibility for providing direct care (Chou, 2000).

Respondent's educational attainment. As caregiving does not occur in isolation from an individual's social and experiential past or present, education can be loosely tied

to socioeconomic status (Raina et al., 2004). Generally, more education leads to higher levels of potential earnings (i.e., income); however, findings related to caregiver burden and parental educational attainment status have been mixed. For example, Kring et al. (2008) found that higher levels of education in parents reported greater burden in parents of children with ASD. In contrast, a more recent study conducted by Cadman at el. (2012) did not find this relationship between parental education and caregiver burden. Similarly, a study conducted by Vogan and colleagues (2014) did not find that higher levels of education lead to higher levels of caregiver burden in their study of 297 parents of adolescents and young adults, ranging in age from 12 to 30 years old, with ASD in Ontario, Canada. It should be noted that the majority of respondents were highly educated (75%), and the lack of diversity could contribute to the lack of association. Findings related to caregiver burden and parental education have been mixed, thus additional research is warranted to examine associations of caregiver burden and parental education.

Household income. Economic resources play an important role in a family's perception of well-being. Income is a primary determinant in how many services a family can purchase to alleviate the burden of caregiving (Chou, 2000). In a study conducted by Vogan and colleagues (2014), found that household income was not associated with burden in a study examining child, parent, and system variables among 297 parents of adolescents and young adults with ASD. This finding could be due to the location of where this study took place, as this study was conducted in Canada, where a government-funded health care system provides services regardless of income (Vogan et al., 2014). Moreover, Shattuck and colleagues (2012) found that children with ASD from

families with higher income had higher adjusted odds of participation in postsecondary employment and education, thus suggesting that it may be easier for parents with higher income to access opportunities for their young adult children in the community.

Respondent's race and ethnicity. Race can affect the intensity of the experience of caregiver burden, as race is often attached to culture and varying cultural values also affect caregiving decisions about the care of children with special health care needs (Chou, 2000). Indeed, Blacher & McIntyre (2006) reported that cultural differences exist in caregiver reports of depression, morale, and positive perceptions in their study of 282 Anglo and Latino caregivers of young adults with ID. It appears race and ethnicity can be differentially experienced by individuals of different races/ethnicities; thus, it is important to examine race and ethnicity to determine if they can affect the level of burden parents feel and in return help inform interventions. More research in this area is warranted as there is limited studies examining the effects of race and ethnicity on caregiver burden among parents of children with ASD.

Family empowerment. Empowerment is defined as "…an intentional, ongoing process… through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group, 1989, p. 2). According to Zimmerman (1995), empowerment can be viewed as a process (incorporating actions, activities, or structures), and it can also be viewed as an outcome (an achieved level of empowerment). The subject of empowerment can be tricky to research, as empowerment is context- and population-specific (Nachshen, 2005). In terms of empowerment in the context of parents of children with disabilities, the term empowerment reflects the parent's active agency and sense of control over themselves,

their child and their family. Singh et al. (1995) described parental empowerment as a process through which families can access knowledge, skills, and resources that enable them to gain positive control over their lives. Parent empowerment has been associated with positive outcomes in families of children with developmental disabilities (Koren, DeChillo & Friesen, 1992). Weiss and colleagues (2015) examined a sample of 156 mothers of children with ASD in a wide range of ages (4 to 21-years old) to investigate how parent empowerment and positive gain are related to their experiences of distress. Results suggested that more child problem behaviors were related to less maternal empowerment, which in turn was related to greater maternal distress, thus supporting empowerment as a partial mediator in their study
(Weiss, MacMullin & Lunsky, 2015).

As shown in Figure 3, the depiction of the conceptual model used for this study in terms of caregiver burden in parents of children with ASD in high school used the stress process model framework. In this prediction model, the interaction between the background and context, stressors, and outcome are thought to be mediated by family empowerment. The statistical analysis looks at the direct links between the background/context variables and outcomes, the direct links between the stressor variables and outcomes, and finally, mediation of both background/context variables and stressor variables. This study will examine the background and context of stress with the variables available to this study, including; the respondent's educational attainment, total household income, the respondent's relationship to the child, and the respondent's race and ethnicity. Stressors, in the context of this study is having a child with ASD and characteristics of that child, such as; the child's grade level, age of ASD diagnosis,

cognitive abilities, academic skills, adaptive skills, the presence of any co-morbidities in addition to ASD, age of the child upon enrollment in the study, ASD symptom severity, and the child's gender. The outcome for this study is caregiver burden. In addition, family empowerment is first considered as part of the process that is taken into account when looking at caregiver burden, then it is examined as a possible mediator between predictor variables and caregiver burden. A mediator variable is a variable that explains the relationship between the independent variable and dependent variable and can produce changes in the dependent variable.

As caregiver burden has been conceptualized in a multitude of ways, a summary of the studies utilizing the term caregiver burden, as well as well-being and/or stress is included in Appendix 1.

Convergence of Findings

In evaluating the four studies that examined multiple factors associated with caregiver burden in caregivers of children with ASD, it can be determined that various themes reoccurred within the literature (Table1; Vogan et al., 2014; Kring et al., 2008; Cadman et al., 2012; & Lin, 2011). All the studies found that parents of children with ASD had high levels of caregiver burden, as well as higher levels of burden than parents of children with other disabilities (e.g., ADHD and Down Syndrome). In addition, all four of the studies considered family background and child characteristics as important factors associated with caregiver burden. Albeit different in each study, there is a consensus that a combination of family and child characteristics can contribute to the variance associated with caregiver burden in parents of children with ASD.

There were also many differences in indicators among the findings within the four

studies (e.g., measures used to assess caregiver burden and ASD symptom severity, etc.). For example, in two of the studies caregiver burden was measured by the Zarit Burden Interview (ZBI; Kring et al., 2008 and Cadman et al., 2012), while Vogan et al. (2014) used a 9-item Caregiver Burden Scale, a subscale of the Revised Caregiver Appraisal Scale, and Lin (2011) used a Caregiver Burden Scale, which included 18 items and developed in Chinese. In addition, ASD symptom severity was measured differently among all four studies. Vogan et al. (2014) used the Social Communication Questionnaire Lifetime, which consists of 40 items that are based on the Autism Diagnostic Interview – Revised (ADI-R). The ADI-R was used in Kring and colleagues (2008) study, while Cadman et al. (2012) used the Autism Quotient-Informant to capture the current severity of ASD symptoms, and Lin's (2011) study utilized a combination of verbal IQ scores and levels of function language and social adaptation to determine the severity of autism diagnosis. Lastly, the country the studies were conducted varied, which can have an impact on family characteristics, such as income and education. For example, both Cadman et al. (2012) and Vogan et al. (2014) studies were conducted in countries with universal health care, (e.g., United Kingdom and Canada respectively), where services are provided regardless of income. Lin's (2011) study was conducted in Taiwan, while Kring et al. (2008) study was conducted in the U.S.

It is also important to note that three of the studies used a comparison group in addition to the children with ASD, and they had smaller sample sizes for the ASD group. For example, in Cadman et al.'s (2012) study of the 192 families caring for a young person, 101 had a diagnosis of ASD, while 92 had a diagnosis of ADHD. In Vogan et al.'s (2014) study of 297 parents of children with ASD, 135 had a diagnosis of ASD only,

while 162 had a diagnosis of ASD and co-morbid ID. Moreover, Lin's (2011) study consisted of 50 adolescents with ASD and did not use a comparison group.

Table 2 shows the inconsistencies of findings among the four studies that examined child characteristics/background variables and caregiver burden.

Table 2.

Inconsistencies of Findings from Previous Studies

	Vogan et al. 2014 n=297	**Cadman et al. 2012 n=192**	**Kring et al. 2008 n=272**	**Lin 2011 n=50**
Child Characteristics				
ASD Comorbid ID		-	+	
ASD Symptom Severity	+	-	+	+
Externalizing Behaviors	+	+		+
Psychiatric Comorbidities	+	+	+	
Adaptive skills				+
Age of Child	-		-	
Gender of Child			-	
Parental/Family Characteristics				
Marital Status	-			
Parental Age	+			
Parental Education	-	-	+	
Household Income	-			
- Not significant in predicting caregiver burden				
+ Significant in predicting caregiver burden				

Note: the sample (n) in this chart are indicative of the whole study, not just ASD specific population within the study

Rationale of Factors

In order to conduct a comprehensive review of literature, the majority of the factors that were examined in the four previous studies were reviewed above, in order of appearance; child characteristics include: age, adaptive skills, cognitive abilities, co-morbidities, ASD symptom severity; while the parent/family characteristics include: caregiver's relationship to the child, parental education attainment, total household

income, and family empowerment. Variables such as parental marital status and parental age will not be included in this study as this information is not available in the dataset.

Research Rationale

Limitations of Previous Research

Limited research suggests that caregiver burden is associated with more severe ASD symptomatology and less functional independence (Lin, 2011); however, caregivers of those with less severe ASD still report clinically significant levels of burden (Cadman et al., 2012). There have been few studies comparing factors that contribute to caregiver burden across all levels of functioning (Vogan et al., 2014). Additionally, the studies previously mentioned, include a variety of factors and high proportions of the variance are still left unexplained. The variables and variance contributing to caregiver burden vary widely from study to study. For example, in Vogan et al.'s (2008) study, who used a multiple regression analysis design, found that child, parent, and systems variables together only accounted for 17% of variance in caregiver burden. These researchers also pointed out homogeneity within their sample (e.g., study limited to primarily mothers, highly educated parents from average to high income households), and suggested research on a larger more diverse sample. Comparatively speaking, Lin's (2011) study used a stepwise multiple regression analysis and found that functional independence, maladaptive behaviors and severity of ASD symptoms accounted for 41.7% of the variance in caregiving burden. Kring et al. (2008) also utilized a stepwise multiple regression analysis in their study and indicated that 30.4% of the variance in maternal burden was accounted for by having a child with higher levels of asocial behavior, more

unpredictable behavior, poorer health ratings, or greater frequency of gastrointestinal problems.

Conclusions

As young adults with ASD generally will have continued impairment in communication skills, social interaction, and independent living skills into adulthood and because fewer services exist to support young adults with ASD through adulthood, they tend to rely heavily on the assistance from family and friends. Previous research has reported high levels of caregiver stress and burden in parents caring for children with ASD than parents of children with other disabilities such as Fragile X syndrome and Down syndrome (Hartley, Seltzer, Head & Abbeduto, 2012; Dabrowska & Pisula, 2011; Smith & Anderson, 2014; Cadman et al., 2012). However, much of the research is inconsistent on what variables contribute to caregiver burden, a more in-depth understanding of these factors commonly associated with caregiver burden in parents of children with ASD, as well as the impact of the variables on caregiver burden is needed.

Purpose of Current Study

This study aims to address research gaps by exploring the relationship between caregiver burden and a number of child and parent/family characteristics in a large, multisite sample. More specifically, this study uses data from a geographically diverse sample within the U.S. Figure 4 is a diagram of how variables are predicted to contribute to caregiver burden, followed by proposed research questions and related hypotheses.

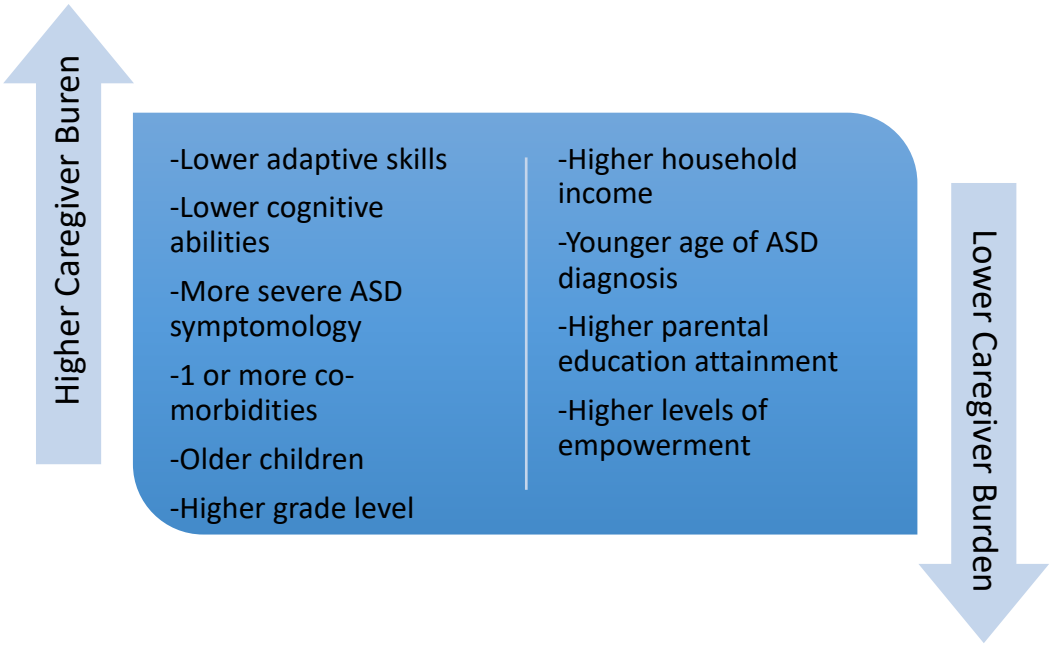

Figure 4. Predicted Relationships Between Caregiver Burden and Child/Family Characteristics

Research Questions and Hypotheses

Research Question 1. What are the significant relationships between child characteristics and caregiver burden in parents of adolescents with ASD?

Hypotheses associated with research question 1.

- Measures of adaptive skills and cognitive abilities are hypothesized to predict caregiver burden with an inverse relationship. Specifically, the lower the adaptive skills and cognitive abilities, the higher the caregiver burden in parents of children with ASD in high school.
- ASD symptom severity as measured by the Social Responsiveness Scale-Second Edition, Teacher (SRS-2) form, the presence of co-morbidities, age of ASD diagnosis, grade in school, and current are hypothesized to significantly predict caregiver burden directly. More specifically, the more ASD symptoms an individual exhibits (the higher the score on the SRS-2), the presence of one or

more co-morbid diagnoses, the older a child is, and higher grade the child is in school are likely to increase caregiver burden, while younger age of ASD diagnosis the lower the caregiver burden in parents of children with ASD.

- Passage Comprehension and Academic Knowledge (measured by subtests of the WJ-III ACH) and gender of the child with ASD are more exploratory in nature as there are few studies in the previous research on caregiver burden in children with ASD.

Research Question 2. What are the significant relationships between family demographic characteristics and caregiver burden?

Hypotheses associated with research question 2.

- Respondent's race and ethnicity are exploratory in nature, as much of the research on family demographics and their contribution to caregiver burden is mixed.
- Total household income, respondent's educational attainment, and family empowerment are hypothesized to predict caregiver burden with an inverse relationship. That is, the higher the total household income, higher educational attainment and higher levels of family empowerment (within each of subscales; Family, Service System, and Community/Political, the lower the level of burden as reported by the caregiver.

Research Question 3. How is empowerment of families associated with caregiver burden?

Hypotheses associated with research question 3.

- Higher scores on the Family Empowerment Scale (FES) are hypothesized to be associated with lower levels of caregiver burden, as higher scores on the FES

indicate higher levels of empowerment.

- In addition, higher scores within each of the three subscales of the FES (i.e., Family, Service System, Community/Political) are hypothesized to be associated with lower levels of caregiver burden.
- Family empowerment is hypothesized to partially mediate the relationship between background/context variables and caregiver burden. In other words, family empowerment is hypothesized to account for some of the relationship between background/context and stressors and caregiver burden.

CHAPTER III: RESEARCH METHODS

This study is a secondary analysis of the Center on Secondary Education for Students with ASD (CSESA) data from a 3-year randomized control trial on high school students with ASD. Participants in this study were part of a larger research project examining the efficacy of a comprehensive treatment model for high school students on the autism spectrum (CSESA), a grant funded by the Institute of Education Sciences through Frank Porter Graham Child Development Institute (FPG). Sixty high schools across three states (North Carolina, California, and Wisconsin) were randomly assigned to the intervention (CSESA) or services-as-usual group. The current study does not address intervention efficacy and only utilizes data collected prior to the intervention; thus, no further distinction between participant groups is made. Baseline data about the student participants were collected from the students with ASD, their teachers, and their parents. Parents also completed measures related to family demographic characteristics (e.g., household income and educational attainment) and personal well-being (e.g., caregiver burden and empowerment).

Procedure

The aim of this study is to examine the relationship between caregiver burden and a variety of child and family characteristics in children with ASD currently in high school, as well as look at how the level of caregiver empowerment is associated with caregiver burden in parents of children with ASD in high school. Three specific research

questions will be addressed: (1) What are the significant relationships between child characteristics and caregiver burden in parents of adolescents with ASD?; (2) What are the significant relationships between family demographic characteristics and caregiver burden? and (3) How is empowerment of families associated with caregiver burden in parents of children with ASD in high school?

Inclusion/Exclusion Criteria

The inclusionary criteria were as follows: (a) students had an Individualized Education Plan (IEP) with a primary or secondary educational label of autism, (b) had at least two years remaining in school, and (c) had family who could complete forms in either English or Spanish. Children and their parents were recruited at each high school site. Schools were given study packets with informational fliers and consent forms to send home to families of all students who met eligibility criteria. The families then mailed the completed consent forms in a pre-addressed, pre-stamped envelope directly to the research staff or returned the study packets to the school. All parents consented to their participation; adolescent assent was conducted at the initial testing session.

Ethical Considerations

This study was conducted in compliance with the University of North Carolina's Institutional Review Board (IRB; #13 – 3002). For the current study, all electronic files from FPG were de-identified prior to receipt of secondary data.

Participants

This study examined child and parent variables among 544 children with ASD. For the purpose of this study participants are considered either "children" or the parent of a child with ASD. The parents of children participating in the study, filled out

demographic information about their child and their own demographic information, and while the data the parent provided was prioritized, supplemental data from the school was used regarding grade, gender, ethnicity and race of the child, if the parent did not complete the demographic form. The child participants in this study are 86% male (n = 469) and 14% female (n = 75), ranging in age from 13 to 20 at the beginning of the research study. In 2012, the CDC estimated the overall prevalence ratio for boys compared to girls was 4.5, thus the study sample is relatively similar to the expected ratio of males to females (Christensen et al., 2012). Of the 544 children who participated in this study, 61.9% of the child's parent identified them as White (n = 337), 12.9% identified as Black or African-American (n = 69), and less than one percent were identified as American Indian/ Alaskan Native (n = 14), Asian (n=23), Multi/Biracial (n= 37), other (n=23), while 8% (n =41) of the sample did not answer the question, and data from the school could not be supplemented. Regarding ethnicity, 18% of the child's parents identified them as Hispanic (n = 103), 75% identified as Non-Hispanic (n = 409), while 5% (n = 32) of the sample did not answer the question, and data could not be supplemented by the school. Of the 544 parents who participated in this study, 58.5% identified themselves as White (n = 318), 11% identified as Black or African-American (n = 60), and less than one percent were identified as American Indian/ Alaskan Native (n = 8), Asian (n = 20), Multi/Biracial (n = 4), other (n = 20), while 20.1% (n = 114) of the sample did not answer the question. Regarding ethnicity, 13.6% identified themselves as Hispanic (n = 74), 66.5% identified as Non-Hispanic (n = 362), while 19.9% (n = 108) of the sample did not answer the question. Participants in this study are of similar diverse racial backgrounds as found by the U.S. Census Bureau in 2018. In 2018, the U.S.

Census Bureau found that 76.5% of the U.S identified as white alone, 13.4% identified as Black or African American alone, 1.3% identified as American Indian and Alaskan Native alone, 5.9% identified as Asian alone, 0.2% identified as Native Hawaiian and Other Pacific Islander alone, and 2.7% identified as two or more races. As far as race and Hispanic origin, 60.4% identified as White alone, Non-Hispanic or Latino and 18.3% identified as Hispanic or Latino (United States [U.S.] Census Bureau, 2018). In addition, parents provided information on additional medical and psychiatric co-morbidities their child had been diagnosed with in addition to ASD. The most common co-morbid diagnosis was attention deficit disorder, occurring in 23.9% of participants (n = 130), followed by anxiety disorder, occurring in 16.7% of participants (n = 91).

Measures

This descriptive, associational study examines the relationship between caregiver burden and a variety of child and family characteristics in children with ASD, as well as empowerment as a possible mediator between the child and family characteristics and caregiver burden. A detailed battery of clinical and psychological tests and questionnaires completed by teachers, research staff, and caregivers, were used to extract specific quantitative information. The measures used for the study are discussed below.

Child and family demographic form. To gather demographic information on participants and their caregivers, the Child and Family Demographic Form was given to the parents of children with ASD to fill out, and included 11 questions related to the child's age, gender, grade level, age of ASD diagnosis, and any diagnosed co-morbidities. Also included on this form were five questions related to the caregivers, such as relationship to the child, caregiver's ethnicity, caregiver's race, caregiver's

educational attainment, and total household income. In addition, there was room for a second caregiver information to be filled out regarding, relationship to the child, ethnicity, race, and highest level of education achieved, which was inconsistently filled out (Appendix 2). For the purpose of this study, it is assumed that the primary caregiver completed the form, thus using their information as caregiver 1. With regard to grade level, 9th, 10th, 11th, 12th, and "other" were the options available to choose from, where "other" would be considered a child repeating a grade, past 12th grade. As children in special education are entitled to educational services until their 21st birthday, they may be repeating 12th grade a number of times and would therefore be considered in an "other" grade.

The Vineland Adaptive Behavior Scales, Second Edition. The Vineland Adaptive Behavior Scales, Second Edition (Vineland-II) assessment was designed to measure adaptive behavior in individuals from birth to 90 years of age and can aid in diagnosing and classifying intellectual disabilities and other disorders such as autism and global developmental delays. The scales of the Vineland-II are organized within a four-domain structure: Communication, Daily Living Skills, Socialization, and Motor Skills. This structure corresponds to the broad domains of adaptive functioning set forth by the American Association of Intellectual and Developmental Disabilities: Conceptual, Practical, and Social (PsychCorp, 2016). Each of the four domains within the Vineland-II have two to three subdomains. The scores for three specific adaptive behaviors domains (i.e., Communication, Daily Living Skills, and Socialization) yield an overall adaptive behavior composite (ABC) score. Questions on the Vineland-II are rated using a 3-point Likert scale format. Response options include, 0 – seldom or never present, 1 –

sometimes present, and 2 – always present. Raw scores are converted to standard scores with a mean of 100 and a standard deviation of 15. The Vineland-II assigns adaptive functioning levels for ranges of standard scores: high (130 – 140), moderately high (115 – 129), adequate (86 – 114), moderately low (71 – 85), and low (20 – 70).

A large normative sample (n=3,695) was used that is representative of the general population in the United States, including ethnicity, gender, and socioeconomic status. Reliability, in terms of split-half reliability coefficients for the composite scores ranged from .84 to .93; and test-retest reliability coefficients for the Composite scores ranged between .86 to .92. Concurrent validity is highly correlated with the Adaptive Behavior Assessment System-Second Edition (ABAS-II), with the overall Adaptive Composite on the Vineland-II and the General Adaptive Composite scores on the ABAS-II correlated at .70 (Community-University Partnership, 2011).

This study utilized the Vineland-II, Teacher Form to obtain a measure of adaptive skills for child participants. A teacher that was familiar with the child participating in the study completed the adaptive rating scales, taking approximately 25 minutes to complete for each child. This study utilized the ABC standard score which includes the Communication, Daily Living Skills, and Socialization domains.

Social Responsiveness Scale, Second Edition. The SRS-2 is a quantitative measure that identifies the presence and severity of social impairment within the autism spectrum. The SRS-2 contains 65-items to assess autistic symptoms across a range of severity based on parent or teacher report of behaviors in a naturalistic environment (Constantino et al., 2003). Each item on the SRS-2 requires a rating on an observed aspect of reciprocal social behavior that is rated using a 4-point Likert scale format.

Response options include, 1- not true, 2 - sometimes true, 3 - often true, and 4 - almost always true. The SRS-2 yields the following treatment subscales: Social Awareness, Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behavior. These subscales yield the overall total score (Constantino & Gruber, 2012). Raw scores are converted to T-scores, with a mean of 50 and a standard deviation of 10. T-score ranges are as follows; T-scores of 76 and higher are considered severe – suggesting that an individual has clinically significant deficits in social functioning that interfere with interactions with others, scores that fall between 66 and 75 are considered moderate – signaling some clinically significant social deficits, scores that fall within 60 to 65 are considered within the mild range – indicating deficiencies in reciprocal social behavior that are clinically significant and may lead to mild to moderate interference with everyday social interactions, and scores of 59 and below are considered to be within the normal limits and indicate that the individual probably does not have social difficulties (Constantino & Gruber, 2012). The SRS-2 includes items related to both autism symptom domains of social communication impairment, and stereotyped/repetitive behaviors (Constantino et al., 2003).

The School-Age Form for the SRS-2 covers ages 4 to 18 years. The School-Age Form yielded a total reliability coefficient of .95 with a large normative sample (n = 1,014) that was representative of the general population in the United States for the school-age sample (Constantino & Gruber, 2012). In regards to validity, the School-Age Form was found to have moderate to high correlations between other rating scales of social behavior and communication (e.g., Social Communication Questionnaire, the Children's Communication Checklist, and the Social and Communication Disorders

Checklist, and the Childhood Autism Rating Scales; Constantino & Gruber, 2012).

In order to measure ASD symptom severity, the SRS-2 Teacher Form was used in this study. It was given to teachers who were familiar with the child participating in the study to complete, taking approximately 15 to 20 minutes for each student. This study utilized total T-scores.

Woodcock-Johnson, Third Edition - Tests of Achievement. The WJ-III ACH is a widely used, individually administered test used to measure overall academic performance. It includes 22 different tests measuring skills in reading, mathematics, oral language abilities, and academic knowledge (Wendling, Schrank, & Schmitt, 2007).

Normative data for the WJ-III ACH was gathered from 8,818 subjects in over 100 geographically diverse U.S. communities, ranging in age from 24 months to 90 years and older. More specifically, the kindergarten through 12th grade sample composed of 4,783 subjects (Schrank et al., 2001). Regarding concurrent validity, the General Intellectual Ability measured by the WJ-III ACH had correlations ranging from .67 to .76, with the full scale or composite scores from the Wechsler Preschool and Primary Scale of Intelligence – Revised and the Wechsler Intelligence Scale for Children – Third Edition (Schrank et al., 2001).

The WJ-III ACH subtests used in this study were Passage Comprehension and the Academic Knowledge (Science, Social Studies, and Humanities subtests are also known as the Academic Knowledge cluster; McGrew et al., 2014). According to Wendling et al. (2007):

> The WJ-III Passage Comprehension test is a complex, conceptually driven processing task that measures the ability to produce the mental representation

> provided by the text during the process of reading. As the examinee reads, the meaning of the passage is derived through constructing mental representations based on concepts from stored knowledge. (pp.7)

The Academic Knowledge cluster of the WJ-III ACH has three subtests including Science, Social Studies, and Humanities, and is considered a measure of comprehension-knowledge (Wendling, Schrank, & Schmitt, 2007 & McGrew, LaForte, & Schrank, 2014). The median test reliability for Passage Comprehension is .88 and .90 for the Academic Knowledge cluster (Schrank et al., 2001).

To measure academic performance, trained research staff administered the Passage Comprehension and the Academic Knowledge cluster of the WJ-III ACH to participants of the study, generally taking 45 minutes per participant. This study utilized the standard scores for each subtest (e.g., a standard score for Passage Comprehension and a standard score for Academic Knowledge cluster) generated by the online scoring software.

Leiter International Performance Scale, Third Edition. The Leiter International Performance Scale, Third Edition (Leiter-3) offers a completely non-verbal measure of intelligence often administered for use with those who are cognitively delayed, non-English, hearing impaired, speech impaired or on the autism spectrum, and can be administered to anyone from 3 to 75 (plus) years of age ("Leiter-3", 2017). The Leiter-3 consists of 10 subtests that measure three major dimensions of cognitive ability – General Intellectual Ability, Nonverbal Memory, and Processing Speed. The Cognitive Battery subtests (four subtests and one alternative) provide a nationally standardized estimate of nonverbal IQ. One of the strengths of the Leiter-3 is the nonverbal nature of

the test, in that administration and responses by the examinee do not require spoken language (Roid & Koch, 2017). The subtests of the Leiter-3 yield a raw score, which are converted to scaled scores, and the sum of the scaled scores yield a cognitive composite score for nonverbal IQ. Scaled scores are normalized standard scores and have a mean of 100 and a standard deviation of 15. Standard score ranges are as follows: extremely high/gifted (150-170); very high/gifted (130-149); high (120-129); above average (110-119); average (90-109); below average (80-89); low (70-79); very low & mild delay (55-69); moderate delay (40-54); and severe delay (30-39).

Standardization for the Leiter-3 was performed on 1,603 nationally stratified individuals. Internal consistency reliability coefficients, for the four subtests used range from .79 to .95. The concurrent validity for the Leiter-3 was established with the WJ-III COG (note that this is a different WJ-III test that was used in this study to assess academic performance - the WJ-III ACH in this study) with correlations ranging from .77 to .92. Additionally, the Leiter-3 was validated with the Stanford Binet – 5th Edition and had a correlation score of .85 (Genseke, 2014).

To measure non-verbal cognitive ability, participants in this study were individually administered four subtests of the Leiter-3 by trained research staff, taking approximately 30 minutes to an hour to administer to each participant. The subtests used in this study included, Figure Ground, Form Completion, Classification/Analogies, and Sequential Order, which are the four subtests needed for a nonverbal IQ composite score.

Family Empowerment Scale. The FES is a 34-item self-reporting scale, developed to measure empowerment in families with children who have emotional, behavioral, and mental disorders, as well as the way that empowerment is expressed

(Koren, Dechillo, & Friesen, 1992). The conceptual framework behind the development of the FES consists of two dimensions; the level of empowerment and the way that empowerment is expressed (Koren, DeChillo, & Friesen, 1992). Each item on the FES is a statement, in which the rater is asked to rate on a 5-point Likert scale format. Response options include, 1 – not true at all, 2 – mostly not true, 3 – somewhat true, 4 – mostly true, 5 – very true. Scores for each of the three subscales (Family, Service System, and Community/Political) are calculated by summing scores for the subscale items and dividing the number of questions within that subscale. Although all subscale scores can be summed to obtain an overall score ranging from 3 to 15, the scoring guide recommends using each subscale rather than an overall score because each subscale addresses a different topic. The *Family* subscale is comprised of 12-items, and is considered the immediate situation at home and primarily involves the parent's management of day-to-day situation. The *Service System* subscale is comprised of 12-items and refers to the parent's working with the service system to obtain services for their child. The *Community/Political* subscale is comprised of 10-items related to legislative bodies, policymakers, and involves the parent advocacy (Kageyama et al., 2016).

The FES was constructed using standard techniques and piloted with 94 parents of children with emotional disabilities (Koren, 1992). Internal consistency of the FES was examined in terms of the three subscales; Family, Service System, and Community/Political, based on the level of empowerment. The coefficient alphas were 0.88 for family, 0.87 for service system, and 0.88 for community/political. Stability as tested through test-rest procedures resulted in Pearson correlations from .77 to .85. In

terms of validity, two analyses of validity were completed which support the correspondence of the FES items to the concepts fundamental to the instrument design (Koren et al., 1992). Sample items include "I feel my family life is under control;" "I understand how the service system for children is organized;" and "I am able to work with agencies and professionals to decide what services my child needs."

In order to measure family empowerment, the FES was given to the caregivers of participants to fill out, taking approximately 10 to 20 minutes to complete. For this study, scoring was done by an unweighted summation of the items on each subscale (Family, Service System, and Political/Community) divided by the number of items within the subscale (e.g., both the Family and Service System subscales have 12 items, while the Political/Community subscale has 10 items). Possible score ranges were 1 to 5 for each of the three subscales, with higher scores indicating higher levels of family empowerment. Cronbach's alphas for the 12-item Family, 12-item Service System, and 10-item Community/ Political subscales were .88, .89, and .87 respectively for this study. The means and standard deviations for each of the subscales were as follows: $M = 4.11$, $SD = .54$ for Family, $M = 4.13$, $SD = .57$ for Service System, and $M = 3.12$, $SD = .78$ for Community/Political.

Zarit Burden Interview. The Zarit Burden Interview (ZBI) is a caregiver self-report measure originally developed to measure strain associated with the care of community-dwelling persons with Alzheimer disease (Zarit, Orr, & Zarit, 1985). Zarit, Reever, & Zarit (1980) originally developed the Burden Interview, a 29-item self-report inventory, which included questions in areas most frequently mentioned by caregivers as problems (e.g., caregiver's health, psychological well-being, finances, social life and the

relationship between the caregiver and the impaired person). The Burden Interview had a 4-point Likert type response scale, with a possible total burden score of 84 (Bachner & O'Rourke, 2007; Zarit et al, 1980). A total burden score was calculated with four of the 29 items were scored in the opposite direction and subtracted from the total (Zarit et al., 1980). The ZBI was later reduced to 22-items, with a 5-point Likert type response scale, and is one of the most commonly used instruments to assess caregiving burden in clinical and research settings (Bachner & O'Rourke, 2007; Al-Rawashdeh, Lennie, & Chung, 2016). It subsequently has been modified for use with a diverse range of patient populations and caregivers, and translated into a variety of languages, such as: French, German, Hebrew, Japanese, Korean, and Chinese (Bachner & O'Rourke, 2007).

The ZBI was given to parents to fill out to assess subjective perception of the personal difficulty and distress associated with their parenting role, as well as objective burden related to caretaking, taking approximately 10 to 15 minutes to fill out (Hartley et al., 2011). This study used an adaptation of the ZBI created by the Waisman Center to examine caregiver burden in parents of children with ASD, ranging in age from pre-adolescent through adult. The adapted ZBI used for this study includes 30 items but only the 29 items were used for inclusion in the score for this study (item 30 was not used in computing the scale score, as it was added to the adapted ZBI as a stand-alone item that focuses more on the future rather than current burden). The adapted ZBI for this study is reflective of the 29-item Burden Interview in terms of items. Response options for this study were on a 3-point Likert scale and included, 0-Not at All, 1-Somewhat, and 2-Extremely. For the purpose of this study, all scores on the ZBI were rescaled from 0, 1, 2 to 1, 2, 3. The total score was calculated by subtracting the sum of the positive items

from the sum of the negative items, with a possible score range of 17 to 75, with higher scores reflecting greater burden. Modifications from the original ZBI for this study included using the words 'son/daughter' instead of 'spouse.' Sample items from the ZBI used in this study include "I feel that my son/daughter currently affects my relationships with other family members and friends in a negative way;" "I feel embarrassed over my son/daughter's behavior;" and "Because of my involvement with my son/daughter, I don't have time for myself." Cronbach's alphas for the 29 scored items on the adapted ZBI used for this study was found to be highly reliable (29 items; $\alpha = .89$). See Appendix 3 for a copy of the adapted ZBI used for this study.

A summary of each variable, how it is measured, and the scale that was used is outlined in Table 3.

Table 3.

Variables and Measures

Variable	**Measure**	**Scale**	**Type of Data**	**Conversion**
Child Characteristics:	Child and Family Demographic Form			
Age (years)		Age: 13 - 21	Continuous	None
Gender		Gender: M = Male; F = Female	Dichotomous	None
Grade Level		Grade: 9th, 10th, 11th, 12, Other	Ordinal	Recategorized: "Other" = 13th grade
Co-morbidities		Disorder is absent: 0; Disorder is present: 1	Dichotomous	None
Age of Diagnosis		Age of Diagnosis: .5 - 20	Continuous	None
Adaptive Skills	Vineland Adaptive Behavior Scales, Second Edition (Vineland-II) Teacher Form	**Standard Score:** Mean: 100 SD:15	Continuous	None
ASD Symptom Severity	Social Responsiveness Scale, Second Edition Teacher Form (SRS-2)	**T-Score** Mean: 50 SD:10	Continuous	None
Academic Performance	Woodcock Johnson Test of Achievement-III (WJ-III ACH)	**Standard Score:** Mean: 100 SD:15	Continuous	None
Cognitive Functioning	Leiter International Performance Scale, Third Edition (Leiter-3)	**Standard Score:** Mean: 100 SD:15	Continuous	None

Variable	Measure	Scale	Type of Data	Conversion
Parent Demographics:	Child and Family Demographic Form			
Caregiver's Ethnicity		Ethnicity: NONHISP = Non-Hispanic; HISP = Hispanic	Dichotomous	None
Caregiver's Race		Race: American Indian/Alaskan Native, Asian, Black or African-American, Native Hawaiian or other Pacific Islander, White, Multi/Biracial, Other	Categorical	None
Respondent's Relationship to child		Relationship: Mother; Father; Other	Categorical	None
Highest level of education		Highest Level of Education: 5th grade or lower; 6th to 8th grade; Partial High School; High School Graduate or GED; Associate degree/Technical Training/Partial College; Bachelor's degree; Master's/Doctorate/Other Professional degree	Categorical	Recategorized: *No High School Diploma* = 5th grade or lower, 6th to 8th grade, and Partial High School; *High School/No Colleg*e = High School Graduate or GED; *Some College* = Associate Degree/Technical Training/Partial College; *Bachelor's Degree or highe*r = Bachelor's degree, Master's/Doctorate/Other professional degree

Variable	Measure	Scale	Type of Data	Conversion
Household Income		Household income: <$20,000; $20,000 - $39,999; $40,000 - $59,999; $60,000 - $79,999; $80,000 - $99,999; >$99,999	Categorical	Recategorized: <$20,000; $20,000 - 59,999; $60,000 - $99,999; >$99,999
Caregiver Empowerment	Family Empowerment Scale (FES)	**Scale Score** = sum of items within the subscale divided by the number of items Family Range: 1 - 5 Service System Range: 1 - 5 Community/Political Range:1 - 5	Continuous	None
Caregiver Burden	Zarit Burden Interview (ZBI)	**Scale Score** = (sum of negative items) - (sum of positive items) ZBI: 17 - 75	Continuous	Rescaled items from 0,1,2 to 1,2,3

Analytic Strategy

Quantitative data were examined and analyzed using the statistical software program R, version 3.6.1 for Mac OS. The analyses reported here are based on pre-test data from a larger longitudinal project examining the efficacy of a comprehensive treatment model for high school students with ASD.

Data screening. First, demographic variables were analyzed and descriptive statistics were computed for all variables. Means and standard deviations were reported for continuous variables, and percentages were reported for categorical variables. Then, the data were visually screened for normality, outliers, and linearity (histograms, scatterplots) and screened for missing values. Tests of normality and power were conducted on the data to serve as the basis for selection of statistics used to analyze the research questions.

In addition, prior to addressing the research questions Pearson product-moment correlations (continuous variables), point biserial (dichotomous variables), Spearman rank correlations (ordinal variables) or analysis of variances (ANOVAs) were conducted to investigate relationships among all predictor variables available to this study (e.g., child and family characteristics) and caregiver burden. Pairwise deletions were used for variables with missing data for all correlations.

Research question 1 analysis. To evaluate the significant relationships between child characteristics and caregiver burden in parents of children with ASD, a correlation matrix was derived of all selected predictor variables available to this study from the larger longitudinal study, including age of the child, ASD symptom severity, cognitive abilities, adaptive skills, and age of ASD diagnosis. An examination of the correlation matrix was made to identify statistically significant relationships among variables that were subsequently included in a

multiple regression analysis. Point-biserial correlations were derived for dichotomous variables (co-morbidities and child's gender) and included in the correlation matrix, while a Spearman rank order correlation coefficient was derived for the child's grade level, as it is an ordinal variable. Variables that were significantly correlated at the $p < .05$ level were selected for inclusion in the multiple regression analyses, and the variables were entered simultaneously in the model in order to test the hypothesis associated with Research Question 1. Listwise deletions were used for variables missing data in the regression analyses.

Research question 2 analysis. Next, an additional correlation matrix was used to evaluate the significant relationships between family demographic characteristics and caregiver burden in parents of children with ASD. This correlation matrix was derived of predictor variables available to this study from the larger longitudinal study, including caregiver's ethnicity, all three subscales of the FES; Family, Service System, and Community/Political and the dependent variable (caregiver burden). Point-biserial correlation was derived for the caregiver's ethnicity, as it is a dichotomous variable, and included in the correlation matrix and Spearman rank order correlations were derived for total household income and primary caregiver's educational attainment, as they are ordinal variables. Finally, one-way ANOVAs were conducted for the caregiver's relationship to the child with ASD and the caregiver's race. An examination of the correlation matrix, Spearman rank order correlations, and ANOVAs was made to identify significant relationships among variables to be included to the multiple regression analysis. Variables that were significantly correlated at the $p < .05$ level were selected for inclusion in the multiple regression analyses, and the variables were entered simultaneously in the model in order to test the hypotheses associated with Research Question 2. Listwise deletions were used for variables missing data in the regression analyses.

Research question 3 analysis. To examine how empowerment of families is associated with caregiver burden, correlations between predictor variables and the dependent variable (i.e., caregiver burden) were derived. Predictor variables were based on the literature, and included variables with mixed results. First, a simple statistical mediation analysis was performed using regression equations based on the Preacher & Hayes' (2008) model of mediation (Figure 6), where X is considered the independent variable, M is considered the mediator variable, and Y is considered the dependent variable. The effect of the independent variable on the mediator is represented by *a*, the effect of the mediator on the dependent variable, controlling for the independent variable is represented by *b*, while c' represents the direct effect of independent variable on the dependent variable after controlling for the proposed mediator. For this study, separate mediation models were run for each significant predictor, thus X would be any significant background/context variable or child characteristic, M is total family empowerment, and Y is caregiver burden. Specifically, using the Mediation package in R, mediation analysis was run with the regression equations, to determine the effects of the mediating variable (e.g., to determine if the mediation effect is statistically significant). As recommended by Preacher (2014), a nonparametric bootstrapping analysis was used to test the mediational model of family empowerment as a mediator of the relationship between ASD symptom severity, co-morbidities, and adaptive skills and caregiver burden in parents of children with ASD.

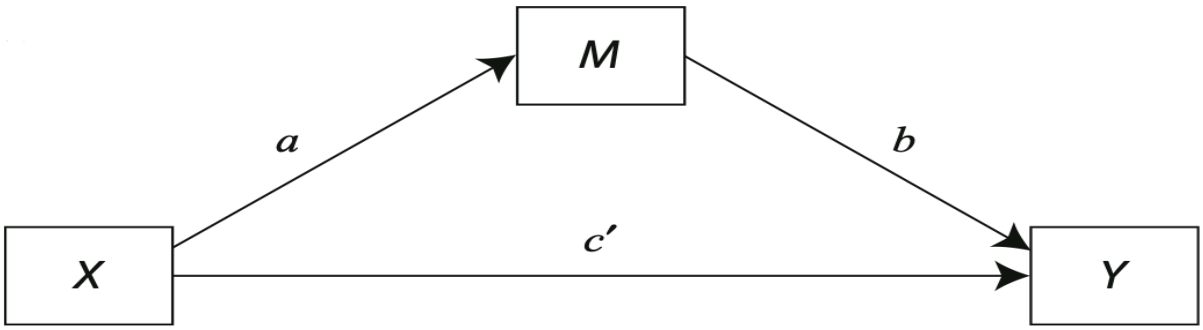

Figure 5. Generic mediation model being tested (based on Preacher & Hayes, 2008).

CHAPTER IV: RESULTS

Introduction

This study posed three research questions to examine the multidimensional factors of caregiver burden in parents of children with ASD. This study used a variety of child and family characteristics, as well as explored family empowerment as a possible mediator of caregiver burden. The research questions were: 1) What are the significant relationships between child characteristics and caregiver burden in parents of adolescents with ASD?; 2) What are the significant relationships between family demographic characteristics and caregiver burden?; and 3) How is empowerment of families associated with caregiver burden?

Preliminary Analysis

Prior to addressing the research questions, descriptive statistics were derived for the study variables, shown in Table 6. In addition, continuous variables were examined for skewness and outliers in the dataset, and assumptions for normality were met.

Table 4.

Descriptive Statistics of Variables

Variable	%	Range	Mean	SD	n
Child Variables					
Age (years)		13-20	16.16	1.44	543
Gender (male)	86.2				544
Grade					533
9th Grade	30.2				
10th Grade	25.52				
11th Grade	27.77				
12th Grade	8.82				
"Other"	7.69				

Variable	%	Range	Mean	SD	n
Age of ASD Diagnosis (years)		.5-20	5.57	3.62	434
Co-morbidities (one or more present)	0.56				443
Cognitive Abilities (Leiter-3)		30-141	85.5	27.25	500
ASD Symptom Severity (SRS-2)		39-110	70.39	12.25	511
Adaptive Skills (ABC score Vineland-II)		30-131	75.73	16.69	465
Passage Comprehension (WJ-III ACH)		1-137	66.31	32.66	506
Academic Knowledge (WJ-III ACH)		1-131	69.07	30.36	496
Parent Variables					
Race (White)	58.5				544
Ethnicity (Non-Hispanic)	66.5				544
Respondent's Relationship to Child (Mother)	72.3				439
Educational Attainment					436
No high school diploma	0.05				
High School diploma or GED	14.9				
No college or some college	30.3				
Bachelor's degree or higher	49.8				
Household Income					430
<$20,000	8.4				
$20,000 - $59,999	29.1				
$60,000 - $99,999	27.4				
>$99,000	35.1				
Caregiver Burden		18-65	32.52	8.75	397
Family Empowerment – total score		6.1-15	11.37	1.68	402
Family		1.25-5	4.11	0.54	424
Service System		1.92-5	4.13	0.57	420
Community/Political		1.1-5	3.12	0.78	414

Note: Parent Variables = primary caregiver filling out the form

Modifications were made to several variables for specific analyses. Many variables were collapsed to obtain a more parsimonious and compact summary of the data. Comorbidities, a categorical variable with 20 categories indicating specific co-morbidities a child has with the option to choose more than one answer (e.g., anxiety disorder, Fragile X syndrome, oppositional defiant disorder, and Tourette syndrome) was collapsed into two categories (i.e., co-morbidities present or not present). In addition, of the 20 options available to check, Asperger's syndrome, autism, and PDD were removed from the analysis before coding, as one of those are expected to be checked, given that inclusionary criteria included an ASD diagnosis. Additionally, the child's

grade level, a categorical variable with five categories (9th, 10th, 11th, 12th, or "other" grade) was converted to an ordinal categorical variable, converting the "other" option to the 13th grade. To answer research question two, household income, a categorical variable with six levels to indicate total household income (<$20,000; $20,000 - $39,999; $40,000 - $59,999; $60,000 - $79,999; $80,000 - $99,999; and >$99,999) was collapsed into four categories (<$20,000; $20,000 - 59,999; $60,000 - $99,999; and >$99,999). Parental educational attainment (i.e., highest level of education), also a categorical variable with seven levels (5th grade or lower; 6th to 8th grade; Partial High School; High School Graduate or GED; Associate degree/Technical Training/Partial College; Bachelor's degree; Master's/Doctorate/Other Professional degree) was collapsed into four variables (no high school diploma, high school or GED, no college or some college, and bachelor's degree or higher).

In addition, Pearson's correlation coefficients were calculated to examine bivariate relationships among the predictor variables (child and family characteristics) and caregiver burden. Correlation is useful for understanding the degree of the relationship between the dependent variable and the predictor variables. Cohen's standard was used to interpret effect size, where a correlation coefficient of .10 is thought to represent a weak or small association; a correlation coefficient of .30 is considered a moderate correlation; and a correlation coefficient of .50 or larger is thought to represent a strong or large correlation (Table 7; Cohen, 1988).

Table 5.

Rules for Interpreting Bivariate Pearson r Values

Effect Size (Cohen)	
0.10	Weak/Small
0.30	Moderate
0.50	Strong/Large

Separate correlation matrices were created for child and family characteristics before examining them for significant associations (Table 8 and Table 9 respectively). For dichotomous categorical variables, point biserial correlations were derived to determine significance between predictor variables and caregiver burden and included in the correlation matrix (e.g., co-morbidities, child gender, and caregiver's ethnicity). Spearman's rank order correlations were conducted on ordinal variables (e.g., child's grade level, caregiver's educational attainment, and total household income). Lastly, for categorical variables with more than two non-ordered categories, one-way ANOVAs were conducted to determine significant relationships (e.g., caregiver's race and respondent's relationship to the child with ASD).

Research question 1. In order to address Research Question 1: *What are the significant relationships between child characteristics and caregiver burden in parents of adolescents with ASD?* independent variables were chosen from the larger dataset available for inclusion in the correlation matrix. The independent variables included in the correlation matrix included age of the child with ASD (age on September 1st of the year the child enrolled in the study), overall adaptive skills (ABC score from Vineland), passage comprehension and academic knowledge (subtests of the WJ-III ACH indicating academic achievement), cognitive abilities, age of ASD diagnosis, ASD symptom severity (SRS-2), as well as the dependent variable, caregiver burden.

Table 6.

Bivariate Pearson Correlation Matrix of Caregiver Burden and Child Characteristics

Variable	1	2	3	4	5	6	7	8	9	10
1. Caregiver Burden	1									
2. Cognitive Ability	-0.09	1								
3. Age	0.07	-0.36**	1							
4. ASD symptom severity	0.17**	-0.27**	0.14**	1						
5. Age of ASD diagnosis	0.09	0.15**	-0.06	-0.17**	1					
6. Passage Comprehension	-0.03	0.77**	-0.33**	-0.35**	0.27**	1				
7. Academic Knowledge	-0.04	0.75**	-0.32**	-0.35**	0.27**	0.93**	1			
8. Adaptive Skills	-0.12*	0.63**	-0.34**	-0.62**	0.24**	0.72**	0.72**	1		
9. *Co-morbidities*	0.15**	0.02	0.01	0.00	0.22**	0.10*	0.11*	0.08	1	
10. *Gender*	-0.04	0.04	-0.01	-0.25**	-0.14**	0.00	0.00	-0.04	-0.09*	1

Note: Pearson correlations were conducted for continuous variables.
Point-biserial correlations for dichotomous variables are italicized.
** Significant at $p < .01$
* Significant at $p < .05$

A review of the correlation matrix in Table 8 indicates that there were positive statistically significant correlations between a child's ASD symptom severity and co-morbidities and caregiver burden. More specifically, parents of children with more severe ASD symptomology and children with one or more co-morbidities in addition to ASD were likely to experience more burden ($r = 0.17$, $p < .01$ and $r = 0.15$, $p < .01$ respectively). In addition, there was a negative statistically significant correlation between a child's adaptive skills and caregiver burden ($r = -0.12$, $p < .05$). That is as a child's adaptive skills increase the level of caregiver burden parents experience decreases. Using Cohen's standard to evaluate the strength of correlation coefficients, where .10 to .29 represents a weak or small association between the two variables, .30 to .49 represents a moderate association, and 0.50 or larger represents a strong or large association, ASD symptom severity, adaptive skills, and co-morbidities were all weakly correlated with caregiver burden (Cohen, 1988; Table 7). Cognitive abilities, age of the child, passage comprehension, academic knowledge, gender of the child, and age of ASD diagnosis were not associated with caregiver burden. To examine the effect of grade level on caregiver burden, Spearman rank-order correlation coefficient was calculated, and indicated that there was a non-significant correlation between the child's grade level and caregiver burden ($r_s = 0.001$, $p = 0.98$).

To examine the extent of the significant relationships found in the correlation, a multiple regression analysis was conducted to identify predictors of caregiver burden using the variables that were significantly correlated at the $p < .05$ level. In this regression, caregiver burden served as the dependent variable, and child characteristics (e.g., ASD severity, adaptive skills, and co-morbidities) as the predictor variables. The results of the regression indicated that the three predictors explained 5% of the variance ($R^2 = .05$, $F(3, 341) = 5.87$, $p < .001$) within this model

(Table 10). It was found that children with one or more comorbidities in addition to ASD, significantly predicted caregiver burden in parents ($\beta = .14$, $p < .01$). In addition, children with more severe ASD symptomology, significantly predicted caregiver burden in parents of children with ASD ($\beta = .14$, $p < .05$).

Table 7.

Multiple Regression Analysis of Child Characteristics and Caregiver Burden

Source	***B***	***SE B***	**β**	***t***	***p***
ASD symptom severity	0.11	0.05	0.14	2.21	0.02*
Adaptive Skills	-0.02	0.03	-0.04	-0.63	0.53
Co-morbidities	2.45	0.92	0.14	2.69	0.00**
R^2	0.05				
Adjusted R^2	0.04				
F	5.86				

** Significant at $p < .01$
* Significant at $p < .05$

Research question 2. Similar to question one, in order to address Research Question 2: *What are the significant relationships between family demographic characteristics and caregiver burden?* Pearson's correlations coefficients were calculated to examine bivariate relationships among the predictor variables (background/context variables) and caregiver burden. The independent variables included in the correlation matrix included all three subscales of the FES; Family, Service System, Community/Political, and the caregiver's relationship to the child with ASD, as well as the dependent variable, caregiver burden.

Table 8.

Bivariate Pearson Correlation Matrix of Caregiver Burden and Background/Context Variables

Variable	**1**	**2**	**3**	**4**	**5**
1. Caregiver Burden	1				
2. *Caregiver's Ethnicity*	-0.03	1			
3. Family subscale of FES	-0.43**	-0.12*	1		
4. Service Systems subscale of FES	-0.27**	-0.05	0.81**	1	
5. Community/Political subscale of FES	-0.20**	-0.09	0.62**	0.68**	1

Note: Pearson correlations were conducted for continuous variables.
Point-biserial correlations for dichotomous variables are italicized.
** Significant at $p < .01$ * Significant at $p < .05$

A review of the correlation matrix indicates that there were negative statistically significant correlations between all three subscales of the FES; Family, Service System, and Community/Political and caregiver burden. More specifically, the more empowered a caregiver reported on the subscales of the FES, the lower their reported levels of caregiver burden ($r = -0.43$, $p < .01$, $r = -0.27$, $p < .01$, and $r = -0.20$, $p < .01$ respectively). Using Cohen's standard to evaluate the strength of correlation coefficients, the Family subscale of the FES was moderately correlated with caregiver burden, while the Service Systems and Community/Political subscales of the FES were weakly correlated with caregiver burden (Cohen, 1988; Table 7). The caregiver's ethnicity was not significantly associated with caregiver burden. Spearman's rank order correlations did not find any statistically significant associations between total household income and caregiver burden and caregiver's educational attainment and caregiver burden. Correlation coefficients, using Cohen's standard indicated that there was a non-significant, weak, negative correlation between the total household income and caregiver burden ($r_s = -0.10$, $p = 0.98$), while there was a very weak, positive correlation between caregiver's educational attainment and caregiver burden ($r_s = 0.05$, $p = 0.30$). Separate one-way ANOVAs were conducted to compare the effects of independent variables with more than two categories (e.g.,

caregiver's race and caregiver's relationship to the child) on the dependent variable (caregiver burden). The ANOVAs indicated that the effect of the caregiver's race (F (6, 540) = 1.24, p = 0.28) on caregiver burden was not significant; however, the ANOVA for the caregiver's relationship to the child with ASD on caregiver burden showed a main effect, F (3, 369) = 3.24, p = 0.02. Because there was a statistically significant effect found, post hoc comparisons using Tukey HSD test were conducted; however, no significant differences were found among the groups (Table 11).

Table 9.

Tukey's Post Hoc Multiple Comparisons for Respondent's Relationship to Child

Groups	Mean Difference	p	95% Confidence Interval	
			Lower Bound	Upper Bound
Mother-Father	2.01	0.21	-0.67	4.68
Other-Father	-2.98	0.66	-9.70	3.73
Other-Mother	-4.99	0.19	-11.43	1.44

Variables that were significantly correlated at the $p < .05$ level were selected for inclusion in multiple regression analyses, and variables were entered simultaneously into the model. In this regression, caregiver burden served as the dependent variable, and family characteristics (e.g., Family, Service System, Community/Political subscales of the FES, and caregiver's relationship to the child) served as the predictor variables (Table 8). The results of the regression indicated that the four predictors explained 21% of the variance (R^2 = 0.21, F (3, 364) = 24.25, p < 0.001) within this model (Table 10).

Table 10.

Multiple Regression Analysis of Family Characteristics and Caregiver Burden

Source	***B***	***SE B***	**β**	***t***	***p***
Family	-10.99	1.35	-0.67	-8.11	0.00***
Service System	3.75	1.30	0.25	2.88	0.00**
Community	0.57	0.70	0.05	0.83	0.41
Respondent's relationship to Child	-0.19	0.64	-0.01	-0.30	0.76
R^2	0.21				
Adjusted R^2	0.20				
F	24.25				

*** Significant at $p < .001$
** Significant at $p < .01$

The Family subscale of the FES ($\beta = -0.67$, $p < 0.001$) was a significant predictor of caregiver burden in parents of children with ASD in high school, as was the Service System subscale of the FES ($\beta = 0.25$, $p < 0.01$), albeit in opposite directions. Both the Community/Political subscale of the FES and the caregiver's relationship to the child were not found to be significant predictors of caregiver burden ($\beta = 0.05$, $p = 0.41$) and ($\beta = -0.01$, $p = 0.76$) respectively. A family empowerment total score was not included in this regression analysis, as Family, Service System, and Community are the subscales within the FES and the family empowerment total score is a sum of the three subscales, it is assumed that the family empowerment total score is reflected within the three subscales.

Research question 3. To approach Research Question Three: *How is empowerment of families associated with caregiver burden?* a correlation matrix was derived between predictor variables (from the research) and the dependent variable (i.e., caregiver burden) to determine the variables to include in the mediation analyses. Predictor variables chosen for inclusion in the correlation matrix include variables that had mixed results in the literature (e.g., cognitive ability, ASD symptom severity, parental education attainment, and a child's adaptive skills) or have shown to predict caregiver burden (e.g., co-morbidities). Using variables that have had mixed

results in the literature in a mediation analysis can help shed light on confounding variables that may be contributing to the mixed results. As shown in Table 13, ASD symptom severity and co-morbidities were statistically significant and positively correlated to caregiver burden and the child's adaptive skills were statistically significant and negatively correlated to caregiver burden. No significant associations were found between caregiver's educational attainment or a child's cognitive abilities and caregiver burden; therefore, they were not included in the mediation analyses.

Table 11.

Correlations Among Predictor and Dependent Variables

Variable	**1**	**2**	**3**	**4**	**5**	**6**
1. Caregiver Burden	1					
2. ASD Severity	0.17**	1				
3. Co-morbidities	0.15**	0	1			
4. Caregiver Educational Attainment	0.03	0.05	-0.05	1		
5. Cognitive Abilities	-0.09	-0.27**	0.02	0.05	1	
6. Adaptive Skills	-0.12*	-0.62**	0.08	0.01	0.63	1

** Significant at $p < .01$
* Significant at $p < .05$

To further investigate this relationship, separate statistical mediation analyses using regression equations were conducted. Within the stress process model (Figure 3) used as the theoretical framework for this study, family empowerment was considered a possible mediator. Mediation analyses were conducted using a simple statistical mediation model using the three predictor variables that were significantly correlated to caregiver burden (e.g., ASD symptom severity, co-morbidities, and adaptive skills) at the $p < .05$ level. Prior to entering the mediator variable, the overall model accounted for 5% of the variance in caregiver burden, F (3, 341) = 5.87, $p < .0001$. Separate regressions were run using the independent variables (e.g., ASD symptom severity, co-morbidities, and adaptive skills) and the mediator (family empowerment total scale score – the total scale score was used as the three subscales are encapsulated in the

total scale score). No significant regression equations were found for the predictors of family empowerment, with nonsignificant regression equations of (F (1, 377) = 0.55, p = 0.46) with an R^2 of 0.001 and (F (1, 400) = 0.05, p = 0.82) with an R^2 of 0.0001 for ASD symptom severity and co-morbidities respectively. In addition, adaptive skills were not found to significantly predict family empowerment F (1, 348) = 2.27, p = 0.13 with an R^2 of 0.006. As there were no significant effects of the independent variable on the mediator, mediation analysis did not continue, as if there is no effect found, mediation cannot occur. Thus, it was concluded that family empowerment is not mediating the effect of child characteristics on caregiver burden.

Alternatively, the independent variables used in the mediation analysis could have a role in determining caregiver burden, but that this effect is only present in the context of low or high levels of empowerment, suggesting more of a moderating role, thus, a simple moderation analysis was performed (Figure 7). As there was no mediating effect found in the analysis, determining whether or not family empowerment has a moderating role can help assist in identifying specific targets for intervention. In this case, if a moderating effect is found, it would suggest that particular caregivers with low or high levels of empowerment may be at risk in the presence of additional co-morbidities, more challenging ASD symptom severity, or more

significant challenges regarding adaptive skills and would speak to the need to target those areas for intervention to help changes in the family empowerment.

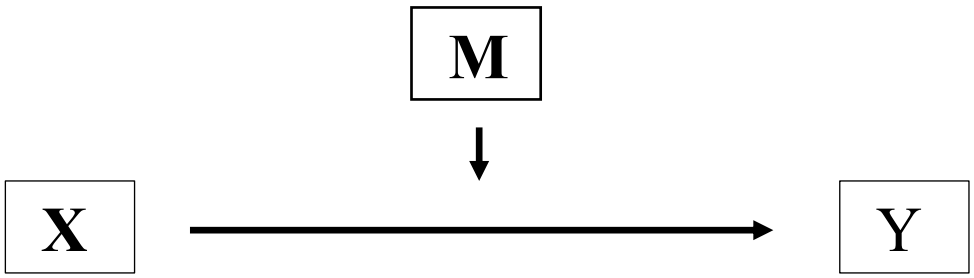

Figure 6. Generic moderation model being tested.

Similar to the mediation analysis, the outcome variable (Y) was caregiver burden, the predictor variables (X) for the analysis were ASD symptom severity, co-morbidities, and adaptive skills, while the moderator variable (M) evaluated for the analysis was family empowerment (i.e., total family empowerment was used as all three subscales of the FES are reflected in the total score). Prior to the moderation analysis, all variables, with the exception of co-morbidities (as co-morbidities is binary there is no need to center it), were mean centered to reduce multicollinearity. Moderation was examined by constructing three hierarchical regression equations that included the independent variables (e.g., ASD symptom severity, co-morbidities, and adaptive skills) and caregiver burden. As with the mediation analysis, separate sets of regression analyses were used for each independent variable. No significant regression equations were found for the predictors of family empowerment, with nonsignificant regression equations of (F (3, 343) = 16.68, p = 0.70) with an R^2 of 0.127 and (F (3, 364) =16.63, p = 0.95) with an R^2 of 0.121 for ASD symptom severity and co-morbidities, respectively. In addition, adaptive skills were not found to significantly predict family empowerment (F (3, 316) = 13.55), p = 0.76 with

an R^2 of 0.114. Thus, there was no evidence family empowerment moderated the associations between caregiver burden and child characteristics.

Table 12.

Family Empowerment as a Moderator of Caregiver Burden

Variable	*B*	*SE B*	LLCI	ULCI	*P*
Constant	32.52	0.44	31.67	33.38	0.000***
FES total	-1.63	0.26	-2.15	-1.12	0.000***
ASD symptom severity	0.11	0.04	0.04	0.18	0.004***
ASD symptom severity * Family empowerment	-0.01	0.02	-0.05	0.04	0.70
Constant	31.15	0.62	29.94	32.36	0.000***
Family empowerment	-1.57	0.37	-2.29	-0.85	0.000***
Co-morbidities	2.56	0.84	0.91	4.21	0.003***
Co-morbidities * Family empowerment	-0.03	0.5	-1.01	0.94	0.95
Constant	32.46	0.46	31.55	33.36	0.000***
Family empowerment	-1.14	1.3	-3.68	1.4	0.38
Adaptive skills	-0.07	0.03	-0.13	-0.02	0.013**
Adaptive skills* Family empowerment	-0.01	0.02	-0.04	0.03	0.72

*** Significant a $p < .001$
** Significant at $p < .01$

As shown in Table 14, interactions between family empowerment and the independent variables, ASD symptom severity (t = -0.07, p = 0.70), co-morbidities (t = -0.07, p = 0.95), and adaptive skills (t = -0.37, p = 0.72), were not significant, indicating an absence of moderation. However, at the same time, consistent with mediation analysis of family empowerment, ASD symptom severity, the presence of co-morbidities in addition to ASD, and adaptive skills emerged as significant predictors of caregiver burden. Plots of the interactions, shown in Figure 8, 9 and 10, show how the estimated slopes at different values of family empowerment are

almost parallel in all analyses, indicating that family empowerment is a non-moderator of the relationship between the independent variables used in the analysis and caregiver burden.

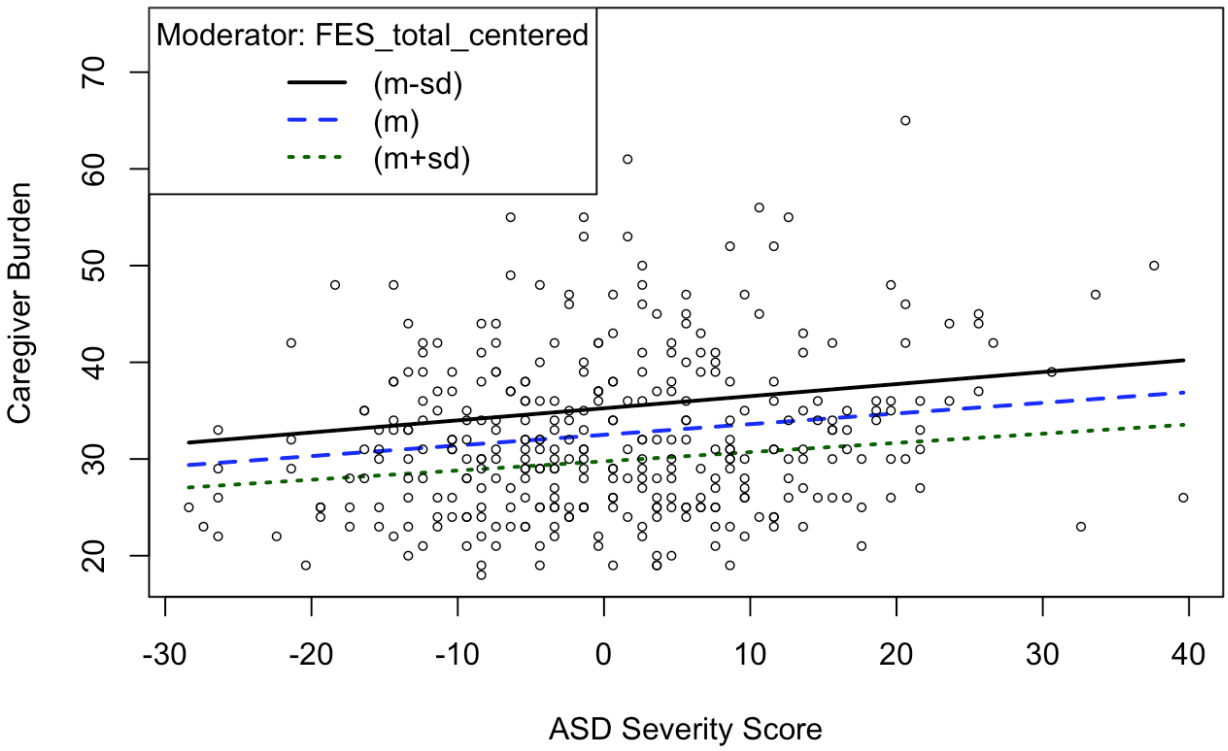

Figure 7. Plot of the interaction of family empowerment and ASD symptom severity.

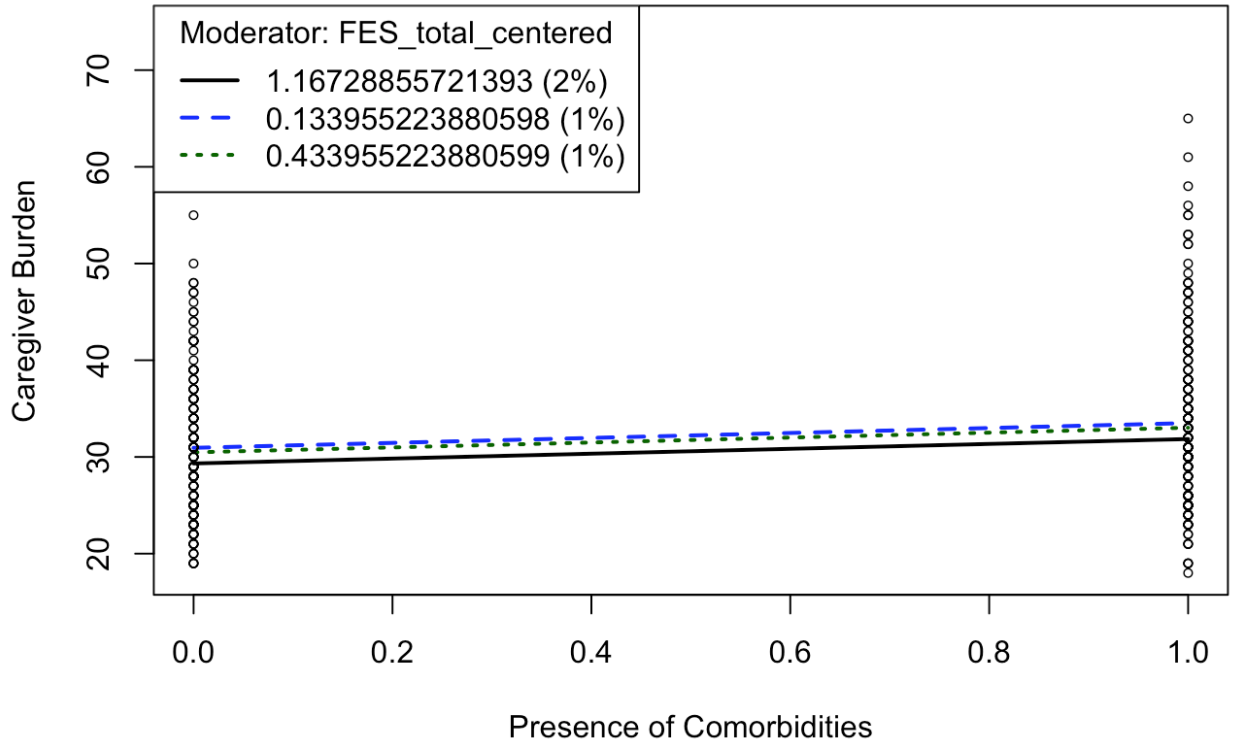

Figure 8. Plot of the interaction of family empowerment and the presence of comorbidities in addition to an ASD diagnosis.

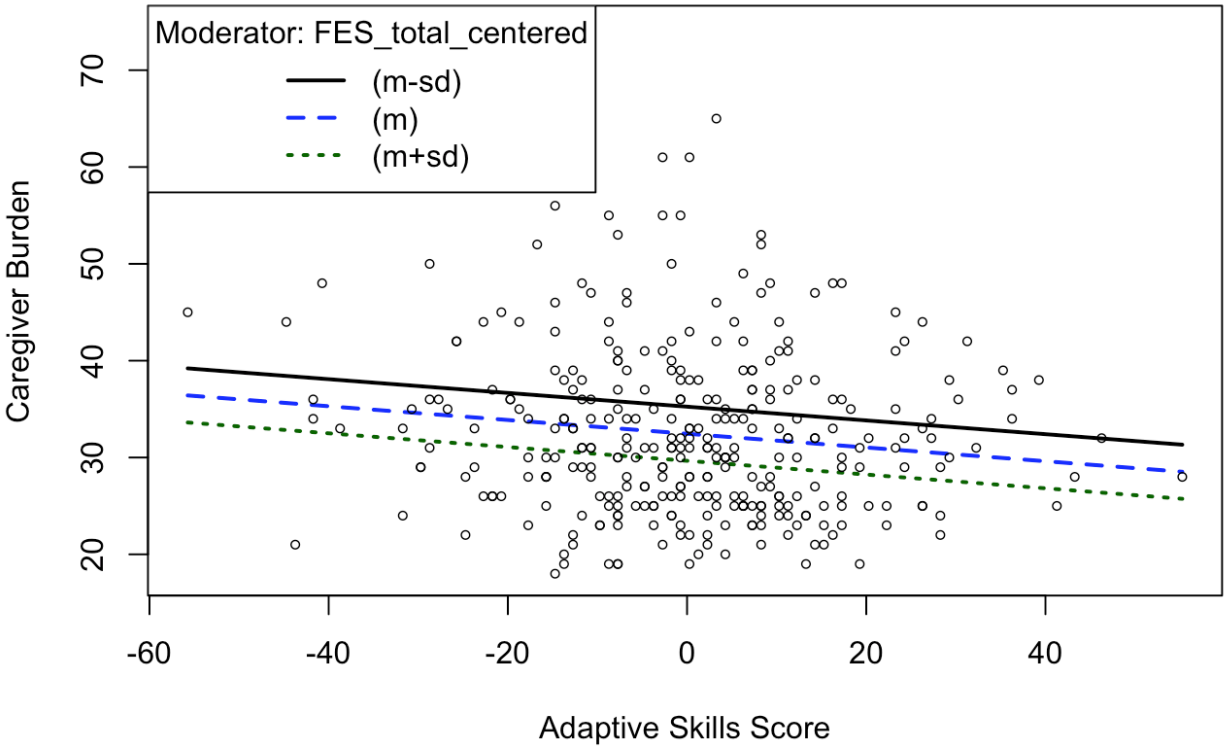

Figure 9. Plot of the interaction of family empowerment and adaptive skills.

These results, considered in context of the broader literature reflect that a variety of child and context/background variables contribute to the level of burden parents of children with ASD experience. In addition, these analyses indicate that family empowerment does not act as a mediator or moderator between the independent predictor variables selected for use in this study and caregiver burden. Furthermore, this study found that statistically significant associations between the presence of co-morbidities in addition to an ASD diagnosis, ASD symptom severity, caregiver relationship to the child (e.g., mother, father, or other), and all three subscales of the family empowerment scale (i.e., Family, Service System, and Community/Political subscales). More specifically, parents of children with more severe ASD symptomology and children with one or more co-morbidities in addition to ASD, reported higher levels of burden, and as a child's adaptive skills increase the level of caregiver burden parents reported decreases. However, after controlling for other factors in the regression equations, children with one or more co-morbid diagnoses in addition to ASD, and the Family and Service System subscales of the FES were found to significantly predict caregiver burden in parents of children with ASD. Of clinical significance, a one-point increase in the Family subscale of the FES led to an approximately ten-point decrease in reported levels of caregiver burden. Thus, concluding that targeting factors that increase empowerment in regards to the Family subscale may help alleviate the experience of burden in caregivers, or may help prevent higher levels of burden from occurring.

CHAPTER V: DISCUSSION

The overarching purpose of this study was to explore the relationships between caregiver burden in parents of adolescents with ASD and a variety of child and family characteristics. In addition, this study examined the relationships among family empowerment and caregiver burden within the stress process model framework (Pearlin et al., 1990). Within this model, family characteristics (e.g., caregiver's educational attainment, caregiver's relationship to the child with ASD, total household income) were conceptualized as the background or context of stress; child characteristics (e.g., cognitive abilities, adaptive skills, age, grade level, age of ASD diagnosis) were conceptualized as stressors and family empowerment was conceptualized as a possible mediator and moderator of caregiver burden, while caregiver burden was considered the outcome. Understanding the multidimensional aspects of caregiver burden may provide important information about factors that can address current gaps in the literature and expand knowledge on the development of successful transition planning for families of adolescents with ASD transitioning out of high school services to help alleviate some of the burden they face during this transition period. Previous research has examined the relationship between child characteristics of children with ASD, context/background characteristics and caregiver burden. Even though the results of this research are mixed and inconsistent, one finding does appear consistent that parents raising a child with ASD show elevated levels of stress and burden as compared to parents of children with other developmental disabilities (Pozo, 2011; Hartley, Seltzer, Head & Abbeduto, 2012; Dabrowska & Pisula, 2010; Smith & Anderson, 2014;

Abbeduto et al., 2008). The present study was designed to provide a broader understanding about the relationships between caregiver burden in parents of children diagnosed with ASD in high school and a variety of child and family characteristics, as well as how family empowerment can possibly play a mediating or moderating role between the child and family characteristics and caregiver burden.

Theories and research on caregiver burden show that it is a multidimensional construct influenced by background/context characteristics (like caregiver emotional and physical health, financial status, social supports, coping skills, etc.) as well as characteristics of the person who is taken care of. This study attempted to look more closely at the background/context and child predictors of caregiver burden experienced by parents of children with ASD within the limitations of the available data. Furthermore, it attempted to examine the role of family empowerment as a possible mediator and moderator of the relationship between those characteristics and the burden these caregivers experience.

Given that this study only used three independent predictor variables for inclusion in both the mediation and moderation analysis within the stress process model framework, despite moderation not being included in the stress process model, perhaps a different framework for understanding the experience of burden families of children with ASD should be utilized in the future. For example, Patterson's (1988) Family Adjustment and Adaptation Response Model includes moderators in its extension of the Double ABCX Model.

Predictors of Caregiver Burden

Child characteristics. The first research question asked, "What are the significant relationships between child characteristics and caregiver burden in parents of adolescents with ASD?" Results, similar to previous findings, indicate statistically significant associations

between child characteristics of children with ASD and caregiver burden. That is, parents of children with one or more co-morbid diagnoses in addition to ASD (Vogan et al., 2014; Kring et al., 2008; and Cadman et al., 2012) and children with more severe ASD symptomology (Vogan et al., 2014; Kring et al., 2008 and Lin, 2011), were found to have higher levels of caregiver burden. Further, this study found that lower adaptive skills were correlated with higher levels of caregiver burden in parents of children with ASD in high school, consistent with Lin's (2011) study showing an association between functional independence and maternal caregiver burden.

No significant associations were found between the child's grade level, cognitive abilities, age of the child, passage comprehension, academic knowledge, gender of the child, and age of ASD diagnosis. It is surprising that both the child's age and the child's grade level were not associated with caregiver burden, given that burden is believed to change as demands and the extent of caregiving involvement change; which presumably increases during the transition out of an entitlement model to a need based medical model of services. Conversely, this lack of association could be better explained by inclusionary criteria for this study. More specifically, to be included in this study children had to have at least two more years of school left, thus the time the parents filled out the ZBI and FES may not necessarily capture the peak transition time as all students had at least two years of school when pretest data collection occurred. Additionally, age is not a consistent reflection of time until transition as some students have more time in school than others (e.g., students on the non-diploma track may have four or five years left before they age out of the special education services compared to only two years for a student on the diploma track). Many of these findings mirror findings in the previous literature, supporting confidence in the findings of this study. For example, Kring et al. (2008) found that both child's age and child's gender were not significant predictors of caregiver well-being, Vogan et al. (2014) found

that the child's age was not associated with burden, and Lin (2011) found that there were no associations between the child's age, age of ASD diagnosis, and gender of the child with caregiver burden. In addition, findings from the present study suggest that a child's cognitive abilities (as measured by the Leiter-3) and academic abilities (as measured by the WJ-III ACH subtests passage comprehension and academic knowledge) do not significantly impact the level of caregiver burden reported by parents of children with ASD. Considering the inconsistencies in previous studies on IQ as a predictor of caregiver burden, this study extends the literature in a larger, more diverse population. Incongruency in the literature on whether or not cognitive abilities are associated with caregiver burden include, Kring et al.'s (2008) study, which found having an ID was related to higher levels of caregiver burden, similar to Vogan et al.'s (2014) findings that the presence of a comorbid ID diagnosis along with ASD was moderately correlated with caregiver burden. Cadman and colleagues (2012) did not find an association between ID and caregiver burden; however, in their study they used the term learning disability interchangeably with ID, so it is not clear if their definition of ID was similar to other studies and more commonly accepted definitions of ID. These inconsistencies in the research could be related to how cognitive abilities were measured and the criteria for having an intellectual disability.

Interestingly, after accounting for the other variables in the model, the results of the regression analysis indicated that co-morbidities and ASD symptom severity were significant in predicting caregiver burden in parents of children with ASD in high school, while adaptive skills were not significant. In this model, ASD symptom severity, adaptive skills, and co-morbidities accounted for 5% of the variance in predicting caregiver burden in parents of children with ASD in high school in this sample (Table 10). Regarding this relationship between whether or not a

child has any additional co-morbid diagnoses in addition to ASD and caregiver burden, the results of this study build upon previous studies that indicated psychiatric co-morbidities were a significant predictor of caregiver burden in parents of children with ASD (Cadman et al., 2012; Vogan et al., 2012; and Kring et al., 2008). Specifically, this study found that parents of children with one or more co-morbidities in addition to ASD report approximately a two-point higher score in levels of caregiver burden. Though statistically significant, this converts to a three percent increase on the level of burden caregivers experience. Since the ZBI does not have normative data, it is difficult to determine if this is a clinically meaningful difference. Nevertheless, the fact that parents of children with ASD and one or more co-morbid diagnoses report higher levels of burden may suggest the need for targeted supports for parents of children with ASD and co-morbid diagnoses, such as access to services that may help alleviate the level of burden.

Family characteristics. The second research question asked, "What are the significant relationships between family demographic characteristics and caregiver burden?" Results of this study found all three subscales of the FES were significantly related to caregiver burden in the expected direction (i.e., negative association). That is, the more empowerment on a subscale of the FES a caregiver reported, the lower the levels of caregiver burden were also reported by the caregiver, which is consistent with Weiss et al. (2015) findings that empowerment was negatively related with distress. More specifically, the Family subscale of the FES was found to be moderately correlated to caregiver burden, while the Service System and Community/Political subscales of the FES to be weakly correlated to caregiver burden. In addition, the caregiver's relationship to the child was found to be statistically significant, however post hoc analysis did not find any significant associations. Findings related to family characteristics that predict

caregiver burden in parents of children with ASD in high school have been mixed in previous research. Kring and colleagues (2008) found there to be associations between caregiver burden and parental education attainment; however, more recent studies did not find this relationship (Cadman et al., 2012 and Vogan et al., 2014). Results from this study did not find any such associations between parental educational achievement and levels of caregiver burden. These inconsistencies suggest there may be context specific variables acting as mediators or moderators between family characteristics and caregiver burden in children with ASD. More research is needed to understand the impact of background and contextual variables on caregiver burden in parents of children with ASD. However, the results from this study, as mentioned earlier (Table 11), in the regression analysis for caregiver burden and family characteristics revealed that 21% of the variance was explained by the four variables (e.g., Family, Service System, and Community/Political subscales, and the caregiver's relationship to the child). More specifically, a one-point increase in the Family subscale of the FES leads to an approximately ten-point decrease in reported levels of caregiver burden. The implications from this can help inform how and when clinicians intervene with families of children with ASD. Conversely, a one-point increase in the Service System subscale leads to an approximately 3.7-point increase in reported levels of caregiver burden. Given that the correlation analysis indicated a negative association (i.e., as one variable increases the other variable decreases, without adjusting for other variables) between the Service System subscale of the FES and caregiver burden, and the regression analysis indicated a positive beta coefficient (i.e., for every 1-point increase in predictor variable the outcome variable will increase by the beta coefficient, which accounts for other variables within the model) between the Service System subscale of the FES and caregiver burden, indicates that when accounting for other variables in the regression equation, the relationship

reverses. Thus, suggesting confounding variables related to both the Service System subscale of the FES and caregiver burden. As previously mentioned, the Service System subscale refers to the parents working with service system, meaning the professionals and agencies providing services to a child, to obtain adequate services for their children (Kageyama et al, 2016). A possible explanation for this is that there are confounding variables that were not accounted for in the model. Additionally, once the subscales of the FES were controlled, the Community/Political subscale and the caregiver's relationship to the child with ASD were no longer significant predictors of caregiver burden in parents of children with ASD. As it seems that there is a complex relationship between the subscales of the FES, using the total score of the FES, instead of the individual subscales of the FES, may have led to different results.

Family empowerment as a mediator of caregiver burden. A mediation analysis was not performed as there were no significant effects of the independent variables on the mediator, which is needed for mediation analysis, thus no mediation effect. The relationship between the independent variables and the family empowerment could be nonsignificant for a variety of reasons. For example, as the FES was designed to have three separate subscales, using a total FES sore could have limited the associations between the independent variables and family empowerment. Additionally, while the current study only focused on three child characteristics, there are many other factors (both child and background characteristics) that are related to caregiver burden that should be examined to further understand the process of family empowerment. In Vuorenmaa et al.'s (2016) study on the associations between family characteristics and parental empowerment, found that parenting-related concerns (i.e., possessing sufficient skills or losing one's temper with children), as well as perceived stress in everyday life were more significant and common in parental empowerment than child-related concerns.

Family empowerment as a moderator of caregiver burden. The moderation analyses did not show any evidence that family empowerment acted as a moderator between the three independent variables chosen for inclusion in the analysis and caregiver burden. Further investigation of family empowerment as a moderator should be examined with a variety of independent variables. Additionally, using the subscales of the FES (i.e., Family, Service System, and Political/Community) may be beneficial to gain more insight into which independent variables family empowerment can influence burden caregivers experience. As the moderation analysis only focused on three child characteristics, it is not surprising that there were no significant findings in the moderation analysis, as parental empowerment refers to the parent's appraisal of their own confidence in managing their own lives and developing coping mechanisms and skills to take control over the decisions that influence their lives and this study did not focus on psychological constructs related to the parents ability to cope (Vuorenmaa et al., 2016).

Limitations

The present study has yielded new information using a diverse, relatively large population sample; however, several limitations need to be considered when interpreting the data. As the analysis for this study used secondary data, one of the overarching limitations is that the study was limited to data that was available. This includes, the modified ZBI used in this study, as the ZBI was initially developed and validated more than 20 years ago for use with informal caregivers of community dwelling persons with Alzheimer disease.

Another issue that may limit generalizability of results is the population from which the students were recruited. The sample is representative of children with an IEP with a primary or secondary educational label of autism and may not be fully representative of all youths with

ASD in the general population in so far as some may not need an IEP to be successful in their education placement. For example, some may be served in other disability categories, as schools do not use the DSM-5 diagnostic criteria to determine eligibility for special education category, some may only need a 504 plan to be successful, or may even be home-schooled. In addition, the population distribution of males to female ratio, is slightly larger than the gender distribution in the autism population at large. More specifically, within the autism population at large the male to female ratio is 4.5:1, while in the present study the sample was majority male (n = 469) with a ratio of 6.3:1 (Christensen et al., 2012).

Next, respondents' (caregivers of children with ASD) knowledge and recollection of diagnosed co-morbidities and related factors may not be accurate. The use of self-report to measure health care utilization may lead to underreporting, the most common problem with this form of data collection according to Bhandari and Wagner (2006). Unfortunately, there was no way of verifying the reports of respondents by checking psychological reports or medical histories. In addition, adaptive skills and ASD severity were not directly observed but measured by the participant's teacher's responses to measures. Using only one informant for a measure may fail to represent the extent of the problem accurately, as factors such as bias and error may play a role in the responses (Stratis & Leecavalier, 2015). Additional information from parents or additional teachers would have helped to provide a more reliable picture of the participant's adaptive skills or ASD severity, as both the Vineland-II and SRS-2 have parent report forms. Moreover, the ratings of the teachers may not be representative of the caregiver's experience of their child's ASD symptoms or adaptive skills.

In addition, the current study employed a cross-sectional study design, limiting inferences about caregiver burden and empowerment. It is likely that levels of empowerment change

throughout the school year and change from the beginning to the end of the school year, as IEP meetings may be held throughout the year. Given that IEP meetings are to support children and to systematically review progress and set new goals, an IEP meeting could lead to more empowerment among parents. The caregiver questionnaires (e.g., ZBI and FES) were collected at the beginning of the school year (around September 1st), in addition, inclusionary criteria for participation in this study included students that had at least two years left of high school at the start of the study, both of which could be contributing to the non-significant findings, as children are still receiving services in high school parents may have not felt the effect of burden yet because students were still at least two years away from graduation.

It is important to recognize that in this study, child characteristics only accounted for approximately 5% of the variance in caregiver burden, and family characteristics accounted for approximately 21% of the variance in caregiver burden in separate models. Though the relationships were significant the associations overall were small. This indicates that there are likely other factors (e.g., caregiver's social support) not assessed or analyzed in this study that contribute to caregiver burden. Within the context of this study, parents of children with ASD had a reported relatively high level of empowerment, as seen in Table 3 (e.g., Family, M = 4.11, Service System, M = 4.13, and Community/Political, M = 3.12). As previously mentioned, the subscales of the FES range from 1 to 5, with higher scores indicating relatively more empowerment in each respective area. This could limit the findings related to mediation using empowerment.

Lastly, this analysis and study is based on a deficits approach to caregiver burden in parents of children with ASD. That is, focusing on the needs and problems in the area that is being studied. As previously mentioned, this is a secondary data analysis and this study did not

examine any variables from a more strength based perspective or protective factors of caregiver burden in parents of children with ASD, as it there were not any variables available to the study. For example, many of the child characteristics variables did not measure abilities that are known in children with ASD and measured more diagnostic criteria abilities (e.g., using cognitive abilities or adaptive skills as criteria for an ID diagnosis). Instead, it may be useful to look at resiliency factors in children with ASD, such as a child's ability to self-advocate or how many meaningful friendships a child has, as these might in fact be associated to lower levels of caregiver burden in parents of children with ASD. Past research has suggested that informal social support can alleviate burden in caregivers (Shiba, Kondo, & Kondo, 2016). In addition, measuring informal social supports a parent has as a protective factor for caregivers, may provide a key area to target when creating interventions to reduce some of the burden parents of children with ASD experience.

Implications for Research and Practice

The results for the current study have important implications for how clinicians can intervene with families of children with ASD. The results from the mediation analyses, were inconclusive about a possible mediator between three independent variables and caregiver burden, but overall found that empowerment was negatively correlated with caregiver burden. In particular, results from this study indicated the Family subscale of the FES can have a rather large impact on caregiver burden, thus interventions should focus on empowering caregivers to manage day-to-day situations when it comes to the caregiving role and future studies should focus on investigating what constructs are in the Family subscale of the FES to help better inform interventions for parents with ASD, which can help alleviate their burden. For example, providing intensive interventions for children with lower adaptive skills to learn and master more

skills may help alleviate the burden parents of children with ASD experience. As teaching and supporting daily living skills in individuals with ASD can foster more independence and decrease the need for others' involvement in their care. Additionally, providing respite care to parents of children with lower adaptive skills can give parents time for self-care needs, which in turn can possibly alleviate some of the burden parents of children with ASD may experience.

Future Research

The sample used in this study was particularly diverse with 74% of the 430 respondents self-identifying as White in response to the question of minority status. As the analysis in this study examined the variation among six degrees of freedom (e.g., six independent groups) for the respondent's race, future studies may want to examine minority status and non-minority status to gain a better understanding of how race is associated with caregiver burden.

The sample used in this study were particularly diverse when it comes to minority status, of the 430 respondents that answered the question, 74% self-identified as White. As the analysis in this study examined the variation among six degrees of freedom (e.g., six independent groups) for the respondent's race, future studies may want to examine minority status and non-minority status to gain a better understanding of how race is associated with caregiver burden.

In addition, future research that focuses on various collection points for the FES and ZBI, for example, beginning of the school year, after an IEP meeting, in the last month of the school year, during the time of transition, as well as post high school, can be helpful in determining critical timepoints throughout the school year and the impact on the level of burden parents of children with ASD experience. For example, do parents experience an increase or decrease in burden throughout the year? Determining times that parents may experience higher levels of burden can be important in terms of when to intervene. In addition, future studies should use a

control group consisting of parents of typically developing children also in the transition into adulthood, as this time might be a period in time that is stressful for all parents of children transitioning out of high school and making preparations for post-secondary placements.

This study and past studies have found that parents of children with ASD in addition to other co-morbidities report higher levels of burden, however it is important to note that with some co-morbidities, symptoms may begin to emerge or even worsen in adolescence and young adulthood, so ongoing monitoring of caregiver burden may be important in parents of children with co-morbid diagnoses in addition to ASD. In addition, future studies might examine this relationship more systematically, in attempts to further dissect what co-morbidities in addition to ASD exacerbate the feelings of burden parents of children with ASD experience. For instance, does the presence of multiple psychiatric co-morbidities or developmental co-morbidities contribute to higher levels of caregiver burden?

In regards to mediation, future studies should focus on how empowerment can mediate other predictor variables of caregiver burden, not measured in the current study. As interventions based on empowerment principles may help alleviate the experience of burden in parents of children with ASD, it is important to determine variables that are positively affected by empowerment.

Conclusions

The focus of this study was to better investigate the multidimensionality of caregiver burden in parents of children with ASD in high school. Previous research has indicated that raising a child with ASD can be a stressful experience, even more so than raising a child with other types of disabilities (Smith & Anderson, 2014), and the current study extends this line of research on the child and family characteristics that are associated with caregiver burden. This

study confirms what other studies have found that the presence of co-morbid diagnoses in addition to ASD and family empowerment are predictive of caregiver burden, but in a larger more diverse sample. This is important because it speaks to the need to provide interventions that empower families to help address the burden parents encounter, and in particular focusing on interventions that impact the immediate situation of caring for a child with ASD and the management of day to day situations, specifically by increasing the level of empowerment within the Family subscale of the FES. It is important to identify both the child and family characteristics that contribute to the burden parents of children with ASD experience, as it can inform the types of interventions or supports that can be provided to the parents of children with ASD transitioning out of high school. Understanding the processes that lead to higher levels of caregiver burden in parents of children with ASD is an important step in mitigating the experiences of burden.

APPENDIX 1: Summary of Studies on Caregiver Burden in Parents of Children with ASD

	Vogan et al., 2014	Cadman et al., 2012	Kring et al., 2008	Lin, 2010	Hartley et al. 2011
Country	Canada	United Kingdom	United States	Taiwan	United States
Diagnoses	ASD/ID	ASD/ADHD	ASD with co-morbidities/ ASD only	ASD	ASD
n	ASD with ID = 162 ASD without ID = 135	ASD = 101 ADHD = 91	ASD with co-morbidities = 142 ASD only = 130	50	91
Age Ranges	12 to 30	14 to 24	10 to 52	10 to 18	11 to 46
Caregiver	Parents	Parents	Mothers	Mothers	Mothers Fathers
Caregiver Burden Measure/ α	Caregiver Burden Scale -subscale of the Revised Caregiver Appraisal Scale - 9 items α = .87 (α = .92)	Zarit Burden Interview- 12 Item	Burden Interview -29 item α = .88	Caregiver Burden Scale - 18 items α = .88 (α = 81)	Burden Interview -29 items (α = .89 = mothers) (α = .86 = fathers)
ASD Symptom Severity Measure	Social Communication Questionnaire- Lifetime Version	Autism Quotient- Informant	Autism Diagnostic Interview-Revised	ASD severity based on a combination of the Verbal IQ scores and levels of functional language and social adaptation	Autism Diagnostic Interview-Revised

	Vogan et al., 2014	Cadman et al., 2012	Kring et al., 2008	Lin, 2010	Hartley et al. 2011
Main Findings	1. Parents of individuals with ASD and ID have high rating in caregiver burden, however burden levels were high across both groups 2. ASD severity, medical comorbidity, internalizing problems, externalizing behaviors, parent age, and inability to pay for services were all strongly correlated with caregiver burden 3. Child age, parent education, marital status, and household income were not associated with caregiver burden	1. Both ADHD and ASD are associated with a high level of caregiver burden, but it was significantly greater in ASD 2. Caregiver burden was mainly explained by the affected person's unmet need 3. Once need was controlled for, severity of ASD was no longer a significant predictor of burden in ASD	1. Higher levels of asocial behavior, more unpredictable behavior, with poorer health rating, or with greater frequency of GI problems were associated with higher levels of maternal burden 2. Co-morbid psychiatric disorder was a significant predictor of maternal burden 3. In addition, when the son or daughter had an ID or lived at home, or when mothers had higher levels of education or higher scores on the BAP measure, levels of burden were higher 4. Child age and gender were not significant predictors of maternal burden	1. There were significant correlations between caregiver burden and severity, maladaptive behaviors and functional independence of adolescent with ASD 2. The greater the severity of autism diagnosis reported, the higher the level of caregiver burden 3. Age and gender of the adolescent with ASD were not correlated with caregiver burden	1. A good marital relationship is a source of support that is related to lower levels of parenting burden 2. Age of the child was negatively related to parenting burden; parents of adolescent reported more burden than parents of adults 3. Parent gender moderated the impact of child health on parenting burden

	Vogan et al., 2014	Cadman et al., 2012	Kring et al., 2008	Lin, 2010	Hartley et al. 2011
Limitations	1. Majority of sample consisted of highly educated parents from average to high income household 2. Limited to primarily mothers (92.9%), and almost all individuals with ASD were living with families 3. Child, parent, and service system factors together only accounted for approximately 17% of the variance in caregiver burden 4. Small sample size of ASD with ID and without ID	1. Some reduction in sample size because of missing data 2. ASD sample appears to be higher functioning than other ASD samples ~15% comorbid learning disability 3. Gender balance of the ASD population was not representative of the general population (male-to-female ratio) 9:1 study vs. 3.3:1 general population 4. Limited to primarily mothers	1. Sample based on maternal reports of their child's diagnoses, which could be subject to error 2. Individuals with diverse co-morbid psychiatric disorders were clustered together 3. No information on validity of the 'Burden Interview' used in the study for use in caregivers of parents of children with ASD 4. Homogeneous sample, 95.1% of ASD and co-morbid and 91.5% of ASD only were white 5. Maternal education was used as a proxy for socioeconomic status	1. Small sample size, without a comparison group 2. Study relied on self-report measures by the mothers 3. 92% of mothers were married	1. Amount of time parents spent with their child with ASD was not measured 2. This study involved married couples, which could bias caregiver burden 3. No information on validity of the 'Burden Interview' used in the study for use in caregivers of parents of children with ASD 4. Mothers' reported on the autism symptoms of child, may not be representative of fathers' experiences

Note: (α) = internal consistency of the measure used in the study

Summary of Studies on Caregiver Stress/Well-being in Parents of Children with ASD

	Abbeduto et al., 2004	Stuart & McGrew, 2009	Blacher & McIntyre, 2006
Country	United States	United States	United States
Diagnoses	Fragile X/ASD/Down Syndrome	Autism/Asperger's syndrome /Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)	ID in addition to: Down syndrome/Autism/ Cerebral palsy/mixed ID
n	Fragile X = 22 ASD = 174 Down syndrome = 39	Autism = 42 Asperger's syndrome = 16 PDD-NOS = 20	Down syndrome = 59 Autism = 23 Cerebral palsy = 87 Mixed ID = 113
Age of Children (years)	10 to 23	Mean age (years) = 4.75	16 to 26
Caregiver	Mothers	Primary Caregivers	Caregivers
Caregiver Burden Measure/ α or Well-Being Measure/ α	Depression = Center for Epidemiologic Studies on Depression Scales Coping = Multidimensional Coping Inventory	Caregiver Strain Questionnaire - 21 items α = .93 (α = .94)	Family Impact Questionnaire - 50 items 2 composites: Negative Impact: (α = .89) and Positive Impact on Parenting: (α = .82)
ASD Symptom Severity Measure	Autism Behavior Checklist	The Gilliam Autism Rating Scale, Second Edition	based on diagnoses given by service agencies in California and met requirements for a diagnosis of autism

	Abbeduto et al., 2004	Stuart & McGrew, 2009	Blacher & McIntyre, 2006
Main Findings	1. The strongest and most consistent predictor of maternal outcomes was the extent and severity of the behavioral symptoms of the adolescent 2. Mothers of individuals with fragile X syndrome displayed lower levels of well-being than those of individuals with Down syndrome but higher levels than mothers of individuals with autism	1. Most families reported high levels of burden following their diagnosis 2. Symptom severity, additional pile-up demands, social support, and the use of passive avoidant coping strategies were strong and consistent predictors of increased burden	1. Caregivers of young adults with autism report more maladaptive behavior problems and lower personal well-being, stress, relative to other diagnostic groups, regardless of cultural group. 2. When behavior problems were controlled for, diagnostic groups accounted for no additional variance in maternal stress or depression
Limitations	1. Narrow assessment of problem behaviors in adolescents, no comparable measures of competence or level of functioning across the three sample 2. Focused only on mothers 3. Not all of the adolescents and young adults with autism in the sample had undergone genetic testing to rule out fragile X syndrome	1. A large portion of the sample was recruited through online sources 2. Not a nationally representative sample - 98.7% mothers, 94.9% White, 86.1% married, 3.8% Hispanic/Latino 3. There may have been construct contamination between measures of negative appraisal, family, and individual burden 4. No comparison group of families with typical children or with other disabilities	1. Homogeneous sample: caregivers limited mostly to mothers (90.7%), the majority were married (75.3%), and more than half of the mothers worked outside of the home (68%). 2. Adaptive functioning in the sample was extremely low (mean: 25, minimum possible: 20)

Note: (α) = internal consistency of the measure used in the study

PLACE ID HERE

APPENDIX 2: Child and Family Demographic Form

Child and Family Demographic Form

Child Demographic Information

1) Child's first and last name: _____

2) Child's date of birth: __ __ / __ __ / __ __ __ __
(Month) (Day) (Year)

3) Child's current chronological age: _____ years old

4) Child's current grade in school. *Choose one answer.*

☐(9)	9th grade
☐(10)	10th grade
☐(11)	11th grade
☐(12)	12th grade
☐(13)	Other ***Specify:*** _____

5) Select your child's gender. *Choose one answer.*

☐	Male
☐	Female

6) Select your child's ethnicity. *Choose one answer.*

☐	Non-Hispanic or Non-Latino
☐	Hispanic or Latino

7) Select your child's race. *Choose one answer.*

☐	American Indian/Alaskan Native
☐	Asian
☐	Black or African-American
☐	Native Hawaiian or other Pacific Islander
☐	White
☐	Multi/Biracial ***Specify:*** _____

☐	Other ***Specify:*** _____

Child Diagnoses

8) Select your child's current diagnoses. *Check all that apply.*

☐(1)	Anxiety disorder
☐(2)	Asperger's syndrome
☐(3)	Attention deficit disorder/hyperactivity (ADD/ADHD)
☐(4)	Autism
☐(5)	Bipolar disorder (manic-depression)
☐(6)	Cerebral palsy
☐(7)	Childhood disintegrative disorder
☐(8)	Depression
☐(9)	Fragile X syndrome
☐(10)	Intellectual disability (also referred to as cognitive disability or mental retardation)
☐(11)	Learning disability
☐(12)	Obsessive-compulsive disorder
☐(13)	Oppositional defiant disorder
☐(14)	Pervasive developmental disorder (PDD-NOS)
☐(15)	Rett syndrome
☐(16)	Schizophrenia
☐(17)	Selective or elective mutism
☐(18)	Tourette syndrome
☐(19)	Tuberous sclerosis
☐(20)	Other ***Specify:*** _____

9) Write the age (in years and months) at which your child was first diagnosed with an autism spectrum disorder (autism OR Asperger's syndrome OR PDD-NOS). *If your child has received more than one of these diagnoses, please write the earliest age of diagnosis.*

Age of diagnosis with ASD	____ years, ____ months of age

10) Select the professional who first diagnosed your child with an autism spectrum disorder (autism OR Asperger's syndrome OR PDD-NOS).*Select one.*

☐(1)	Developmental Pediatrician
☐(2)	Neurologist
☐(3)	Pediatrician
☐(4)	Psychiatrist
☐(5)	Psychologist at clinic
☐(6)	Psychologist at school
☐(7)	Clinic-based assessment team
☐(8)	School-based assessment team
☐(9)	Other ***Specify:*** _____
☐ (10)	Unknown

Home or Community-Based Services

11) Indicate the services and supports that your child is currently receiving ***outside of school*** (at home, in a clinic, or out in the community). *Select 'no' or 'yes' for each of the services. If you select 'yes', indicate the number of minutes per month of service that your child currently receives.*

	Type of service/support	**No**	**Yes**	**Minutes per month**
11.1	Speech/language	☐	☐	_____ minutes/month
11.2	Occupational therapy	☐	☐	_____ minutes/month
11.3	Physical therapy	☐	☐	_____ minutes/month
11.4	Counseling	☐	☐	_____ minutes/month
11.5	Social Skills Group	☐	☐	_____ minutes/month
11.6	Vocational Rehabilitation	☐	☐	_____ minutes/month
11.7	Other ***Specify:*** _____	☐	☐	_____ minutes/month

CSESA
The Center on Secondary Education for Students with Autism

Parent/Caregiver Demographic Information

Fill out both columns for your child's two primary caregivers. *Select one answer for each question.*

Caregiver 1 (CG1)

12.1 Relationship to child:

☐	Father
☐	Mother
☐	Other ***Specify:*** _____

13.1 CG1's Ethnicity (*Select one)*

☐	Non-Hispanic or Non-Latino
☐	Hispanic or Latino

14.1 CG1's Race (*Select one)*

☐	American Indian/Alaskan Native
☐	Asian
☐	Black or African-American
☐	Native Hawaiian or other Pacific Islander
☐	White
☐	Multi/Biracial ***Specify:*** _____
☐	Other ***Specify:*** _____

15.1 CG1's Highest level of education completed *(Select one)*

☐	5th grade or lower
☐	6th to 8th grade
☐	Partial High School
☐	High School Graduate *or* GED
☐	Associate degree *or* Technical Training *or* Partial College
☐	Bachelor's degree
☐	Master's *or* Doctorate *or* other professional degree

Caregiver 2 (CG2)

12.2 Relationship to child:

☐	Father
☐	Mother
☐	Other ***Specify:*** _____

13.2 CG2's Ethnicity (*Select one)*

☐	Non-Hispanic or Non-Latino
☐	Hispanic or Latino

14.2 CG2's Race (*Select one)*

☐	American Indian/Alaskan Native
☐	Asian
☐	Black or African-American
☐	Native Hawaiian or other Pacific Islander
☐	White
☐	Multi/Biracial ***Specify:*** _____
☐	Other ***Specify:*** _____

15.2 CG2's Highest level of education completed *(Select one)*

☐	5th grade or lower
☐	6th to 8th grade
☐	Partial High School
☐	High School Graduate *or* GED
☐	Associate degree *or* Technical Training *or* Partial College
☐	Bachelor's degree
☐	Master's *or* Doctorate *or* other professional degree

16) Select the category that matches your household's pre-tax income in 2013.

☐	< $20,000
☐	$20,000-$39,999
☐	$40,000-$59,999
☐	$60,000-$79,999
☐	$80,000-$99,999
☐	> $99,999

This is the end of the questionnaire. Please look it over for questions you may have skipped and complete those as well.

Thank you for completing this form!

APPENDIX 3: Adapted ZBI

PLACE ID HERE

ZBI

Instructions: These next statements ask about your feelings about your son/daughter. Please circle the number that corresponds to the answer that best describes your response to each statement.

	Not At All	Somewhat	Extremely
1. I feel resentful of other relatives who could, but who do not, do things for my son/daughter.	⓪	①	②
2. I feel that my son/daughter makes requests which I perceive to be over and above what he/she needs.	⓪	①	②
3. Because of my involvement with my son/daughter, I don't have enough time for myself.	⓪	①	②
4. I feel stressed between trying to give to my son/daughter as well as to other family responsibilities, job, etc.	⓪	①	②
5. I feel embarrassed over my son/daughter's behavior.	⓪	①	②
6. I feel guilty about my interactions with my son/daughter.	⓪	①	②
7. I feel that I don't do as much for my son/daughter as I could or should.	⓪	①	②
8. I feel angry about my interactions with my son/daughter.	⓪	①	②
9. I feel that in the past, I haven't done as much for my son/daughter as I could have or should have.	⓪	①	②
10. I feel nervous or depressed about my interactions with my son/daughter.	⓪	①	②
11. I feel that my son/daughter currently affects my relationships with other family members and friends in a negative way.	⓪	①	②
12. I feel resentful about my interactions with my son/daughter.	⓪	①	②
13. I am afraid of what the future holds for my son/daughter.	⓪	①	②
14. I feel pleased about my interactions with my son/daughter.	⓪	①	②
15. It's painful to watch my son/daughter age.	⓪	①	②

	Not At All	Somewhat	Extremely
16. I feel useful in my interactions with my son/daughter.	⓪	①	②
17. I feel my son/daughter is dependent.	⓪	①	②
18. I feel strained in my interactions with my son/daughter.	⓪	①	②
19. I feel that my health has suffered because of my involvement with my son/daughter.	⓪	①	②
20. I feel that I am contributing to the well-being of my son/daughter.	⓪	①	②
21. I feel that the present situation with my son/daughter doesn't allow me as much privacy as I'd like.	⓪	①	②
22. I feel that my social life has suffered because of my involvement with my son/daughter.	⓪	①	②
23. I wish that my son/daughter and I had a better relationship.	⓪	①	②
24. I feel that my son/daughter doesn't appreciate what I do for him/her as much as I would like.	⓪	①	②
25. I feel uncomfortable when I have friends over.	⓪	①	②
26. I feel that my son/daughter tries to manipulate me.	⓪	①	②
27. I feel that my son/daughter seems to expect me to take care of him/her as if I were the only one he/she could depend on.	⓪	①	②
28. I feel that I don't have enough money to support my son/daughter in addition to the rest of our expenses.	⓪	①	②
29. I feel that I would like to be able to provide more money to support my son/daughter than I am able to now.	⓪	①	②
30. I worry about what will happen to my son/daughter when I can no longer care for him/her.	⓪	①	②

REFERENCES

Abbeduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G. & Murphy, M.M. (2008). Psychological wellbeing and coping in mothers of youths with autism, Down Syndrome, or Fragile X syndrome. *American Journal on Mental Retardation.* 109, 237-254.

Al-Rawashdeh, S. Y., Lennie, T. A., & Chung, M. L. (2016). Psychometrics of the Zarit Burden Interview in caregivers of patients with heart failure. *Journal of Cardiovascular Nursing.* 31(6), E21-E28. doi: 10.1097/JNC.0000000000000348

American Psychiatric Association. (2013). Autism spectrum disorders. *Diagnostic and Statistical Manual of Mental Disorders.* (5th Ed.). Washington, DC.

Anderson, C. J., & Colombo, J. (2009). Large tonic pupil size in young children with autism spectrum disorder. *Developmental Psychobiology*, 51, 207-211.

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism: The international Journal of Research and Practice*, *18*(5), 562–570. doi:10.1177/1362361313481860

Bachner, Y. G. & O'Rourke, N. (2007). Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging & Mental Health.* 11(6), 678-685. https://doi.org/10.1080/13607860701529965

Baio, J. (2014). Prevalence of autism spectrum disorder among children aged 8 years. *Center for Disease Control and Prevention: Autism and Developmental Disabilities Monitoring Network,* 63, 1-21.

Bhandari, A. & Wagner, T. (2006). Self-reported utilization of health care services: Improving measurement and accuracy. *Medical Care Research and Review,* 63(2): 217-315.

Blacher, J. & McIntyre, L. L (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research.* 50(3), 184-198.

Boulet, S. L., Boyle, C., & Schieve, L.A. (2009). Health care use and health functional impact of developmental disabilities among US children, 1997-2005. *Archives of Pediatrics and Adolescent Medicine,* 163, 19-26.

Cadman, T., Eklund, H., Howley, D. et al., (2012). Caregiver burden as people with autism spectrum disorder and attention-deficit /hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child &*

Adolescent Psychiatry, 51(9), 879-888.

Chiri, G. & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal, 16(5),* 1081-1091.

Christensen, D. L., Braun, K., Baio, J., Bilder, D., Charles, J., Constantino, J.N., Daniels, J., Durkin, M.S., Fitzgerald, R.T., Kurzius-Spencer, M., Lee, L., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate, M.S., Zahorodny, W., Yeargin-Allsopp, M. (2018). Prevalence and Characteristics of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *Morbidity and Mortality Weekly Report Surveillance Summaries,* 65(13), 1 – 23.

Christensen, D. L., Baio, J., Braun, K. V., et al. (2012). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States. Morbidity and Mortality Weekly Report, Surveillance Summary, 2016;65(No. SS-3) (No. SS-3):1–23.

Cho, S. & Kahng, S. K. (2015). Predictors of life satisfaction among caregivers of children with developmental disabilities in South Korea. *Asian Social Science.*11(2)1911-2025. doi: 10.5539/ass.v11n2p154

Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing.* 15(6), 398-407. doi: 10.1053/jpdn.2000.16709

Cohen, J. (1988). *Statistical Power Analysis for Behavioral Sciences (2*nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

Community-University Partnership for the study of Children, Youth, and Families (2011). *Review of the Vineland Adaptive Behavior Scales-Second edition (Vineland-II).* Edmonton, Alberta, Canada.

Comrey, A., & Lee, H. (1992). A first course in factor analysis. Hillsdale, NJ: Erlbaum.

Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M. et al. (2003). Validation of a brief quantitative measure of autistic traits: Comparison of the social responsiveness with the autism diagnostic interview-revised. *Journal or Autism and Developmental Disorders.* 33(4), 427-433. doi: 10.1023/a:1025014929212

Constantino, J. N. & Gruber, C. P. (2012). Test review: Social responsiveness scale-second edition (SRS-2). Torrance, CA: Western Psychological Services.

Cornell Empowerment Group. (1989). Empowerment and family support. *Networking Bulletin,* 1, 1-23.

Cummings, J. R., Lynch, F. L., Rust, K. C., Coleman, K. J., Madden, J. M., Owen-Smith, A. A.,

et al. (2016). Health services utilization among children with and without autism spectrum disorders. *Journal of Autism and Developmental Disorders, 26(3),* 910-920.

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research,* 54(3), 266-280.

Genseke, K. (2014). History of the Leiter international performance scale (Leiter)[PowerPoint slides]. Retrieved from: https://www.slideserve.com/eyal/leiter-3-training.

George, L. K. & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26(3), 253-259. https://doi.org/10.1093/geront/26.3.253

Grad, J. & Sainsburty, P. (1966). Problems of caring for the mentally ill at home. *Proceedings of the Royal Society of Medicine,* 59(1), 10-23. https://doi.org/10.1177/003591576605900110

Harper, A., Dyches, T.T., Harper, J., Roper, S.O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 43*(11), 2604-2616. doi: http://dx.doi.proxy1.calsouthern.edu/ 10.1007/s10803-013-1812-0

Hartley, S. L., Barker, E.T., Seltzer, M.M., Greenberg, J.S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescent with adults with autism. *American Journal on Intellectual and Developmental Disabilities.* 116(1), 81-95. doi:10.1352/1944-7558-116.1.81

Hartley, S. L., Seltzer, M. M., Head, L., & Abbeduto, L. (2012). Psychological well-being in father of adolescents and young adults with Down syndrome, fragile X syndrome, and autism. *Family Relations,* 61(2), 327-342.

Hayes, A. F. & Rockwood, N. J. (2016). Regression-based statistical mediation and moderation analysis in clinical research: Observations, recommendations, and implementation. *Behavior Research and Therapy.* 98, 39 – 57.

Hyman, S. L., Levy, S. E. & Myers, S. M. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics.* 145(1): 1-5. doi: 10.1542/peds.2019-3447

Interagency Autism Coordinating Committee (IACC). IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research —2013 Update. April 2014. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategicplan/ 2013/index.shtml.

Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2010). Stress process model for individuals with dementia. *Gerontologist; 50(3):*294 – 302. doi: 10.1093/geront/gnp162

Kageyama, M., Nakamura, Y., Kobayashi, S., & Yokoyama, K. (2016). Validity and reliability of the family empowerment scale for caregivers of adults with mental health issues. *Journal of Psychiatric and Mental Health Nursing.* 23, 521-531.

Kanner, L. 1943. Autistic disturbances of affective contact. Nervous Child, 2:217–250.

King, G., King, S., Rosenbaum, P., Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology.* 24(1), 41-53. doi: 10.1093/jpedsy/24.1.41

Kirby, A. V., White, T. J., & Baranek, G. T. (2015). Caregiver strain and sensory features in children with autism spectrum disorder and other developmental disabilities. *American Journal on Intellectual and Developmental Disabilities.* 120(1), 32-45.

Kring, S. R., Greenberg, J. S., & Seltzer, M. M. (2008). Adolescents and adults with autism with and without co-morbid psychiatric disorders: Differences in maternal well-being. *Journal on Mental Health Research in Intellectual Disabilities. 1(2),* 53-73.

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology,* 37, 305-321.

Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research*. 49(2), 111-124. doi: 10.1111/j.1365-2788.2004.00599.x

Leiter-3 Leiter International Performance Scale, Third Edition. (2017). Retrieved October 10, 2017 from https://www.wpspublish.com/store/p/2840/leiter-3-leiter-international-performance-scalethirdedition?gclid=CjwKCAjw3_HOBRBaEiwAvLBbou9c17Iikmt9S-tnBUseu21ZVfSF4k6spzSrdszx8L1SeXFI5GrsVxoCgP0QAvD_BwE.

Lee, L. C., Harrington, R. A., Louie, B. B., Newschaffer, C. J. (2008). Children with autism: quality of life and parental concerns. *Journal of Autism and Developmental Disorders,* 38(6), 1147 – 60.

Lipkin, P. H., Okamoto, J., and the Council on Children with Disabilities and Council on School Health. (2015). The Individuals with Disabilities Education Act (IDEA) for children with special educational needs. *American Academy of Pediatrics,* 136(6), e1650 -166. DOI: 10.1542/peds.2015-3409 originally published online November 30, 2015

Levy, S. E., Giarelli, E., Li-Ching, L., Schieve, L. A., Kirby, R.S., Cuniff, C., et al. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical

conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics,* 31, 267-275.

Lin, L. (2011). Factors associated with caregiver burden and maternal pessimism in mothers of adolescents with autism spectrum disorder in Taiwan. *Occupational Therapy International,*18, 96-105.

Malmberg, D. B. (2007) Assessment of a collaborative parent education program targeting rigid and ritualistic behaviors of children with autism. (Doctoral dissertation). Retrieved from ProQuest Dissertations Publishing. (UMI Number: 3272604)

Mao, A. R. (2012). The factors that contribute to caregiver burden for parents of children with autism spectrum disorder or attention-deficit/hyperactivity Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry,* 51(9), 864-866.

McCubbin, H. I. & Figley, C. R. (Eds.), *Stress and the Family: Volume I: Coping With Normative Transitions* (Vol. I, p 5 – 25). New York: Brunner/Mazel.

McGrew, K. S., LaForte, E. M., & Schrank, F.A. (2014) Technical Manual. *Woodcock Johnson IV.* Rolling Meadows, IL: Riverside.

Montgomery, R. J., Stull, D. E., & Borgatta, E. F. (1985). Measurement and the analysis of burden. *Research on Aging.* 7(1), 137-152. https://doi.org/10.1177/0164027585007001007

Nachshen, J. S. (2005). Empowerment and families: Building bridges between parents and professionals, theory and research. *Journal on Developmental Disabilities,* 11(1), 67-76.

National Institute of Neurological Disorders and Stroke. (2014). Autism Fact Sheet. Retrieved October 9, 2017, from https://www.ninds.nih.gov/Disorders/All-Disorders/Autism-Spectrum-Disorder-Information-Page

Oh, J., An J. W., Oh, S. I., Kim, J. A., Kim, S. H., Lee, J. S. (2015). Depression and caregiving burden in families of patients with amyotrophic lateral sclerosis. *Journal of Korean Acadamy of Nursing.*45(2*):*202-210.

O'Rourke, N., & Wenaus, C. A. (1998). Marital aggrandizement as a mediator of burden among spouses of suspected dementia patients. *Canadian Journal on Aging.* 17, 384-400.

Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social Behavior.* 22(4), 337-356. doi: 10.2307/2136676

Pearlin, L. I., Mullan, J. T., Semple S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist.* 30(5): 583-594. doi: 10.1093/geront/30.5.583

Peer, J.W. & Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: a review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities.* 11(2), 92-98.

Pozo, P. (2011). *A Comprehensive Book on Autism Spectrum Disorders.* Retrieved from https://www.intechopen.com/books/a-comprehensive-book-on-autism-spectrum-disorders/psychological-adaptation-in-parents-of-children-with-autism-spectrum-disordershttps://www.intechopen.com/books/a-comprehensive-book-on-autism-spectrum-disorders/psychological-adaptation-in-parents-of-children-with-autism-spectrum-disorders

Preacher, K. J. (2014). Advances in Mediation Analysis: A survey and synthesis of new developments. *The Annual Review of Psychology,* 66:825 -852.

Preacher, K. J. & Hayes, A. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods.* 40(3): 879-891. doi:10.2758/BRM.40.3.879

PsychCorp. (2016). Clinical Psychology. Retrieved September 1, 2017, from https://www.pearsonclinical.com/psychology/products/100000668/vineland-adaptive-behavior-scales-second-edition-vineland-ii-vineland-ii.html?origsearchtext=vineland

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., … Wood, E. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatrics,* (4)1. doi: 10.1186/1471-2431-4-1

Roid, G. & Koch, C. (2017). Leiter-3: Nonverbal cognitive and neuropsychological assessment. In *Handbook of Nonverbal Assessment* (pp. 127-150). doi: 10.1007/978-3-319-50604-3_8

Rucker, D. D, Preacher, K. J., Tormala, Z. L., & Petty, R. E. (2011). Mediation analysis in social psychology: Current practices and new recommendations. *Social and Personality Psychology Compass, 5(6): 359-371.*

Schrank, F. A., McGrew, K. S., & Woodcock, R. W. (2001). *Technical Abstract* (Woodcock-Johnson III Assessment Service Bulletin No. 2). Itasca, IL: Riverside Publishing.

Segert, R. J., Jackson, D. M., Tennant, A. & Turner-Stokes, L. (2010). Factor analysis and rasch analysis of the Zarit burden interview for acquired brain injury carer research. *Journal of Rehabilitation Medicine.* 42: 302-309.

Seltzer, M.M., Krauss, M.W., Shattuck, P.T., Orsmond, G., Swe, A., Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders,* 33(6), 565-581.

Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among adults with an autism spectrum disorder. *Archives of Pediatrics and Adolescent Medicine,* 165(2), 141-146.

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, *129*(6), 1042–1049. doi:10.1542/peds.2011-2864

Shandra, C. L. & Hogan, D. P. (2009). The educational attainment process among adolescents with disabilities and children of parents with disabilities. *International Journal of Disability, Development, and Education,* 56(6): 363-379. doi: 10.1080/10349120903306616

Shiba, K., Kondo, N., & Kondo, K. (2016). Informal and formal social support and caregiver burden: The AGES caregiver survey. *Journal of Epidemiology,* 26(12), 622-628. https://doi.org/10.2188/jea.JE20150263

Shimabukuro, T. T, Grossee, S. D., Rice, C. (2008). Medical expenditures for children with an autism spectrum disorder in a privately insured population. *Journal of Autism and Developmental Disorders.* 38(3): 546-552.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., Baird, G. (2008). Psychiatric disorder in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of American Academy Child Adolescent Psychiatry;* 47(8); 921 – 929.

Singh, N., Curtis, W. J., Ellis, C. R., Nicholson, M. W., Villani, T. M., & Wechsler, H. A. (1995). Psychometric analysis of the Family Empowerment Scale. *Journal of Emotional and Behavioral Disorders,* 3, 85-91.

Small, S. A., Eastman, G., & Cornelius S. (1988). Adolescent autonomy and parental stress. *Journal of Youth and Adolescence.* 17(5), 377-391.

Smith, L.E. & Anderson, K.A. (2014). The role and needs of families of adolescents with ASD. *Remedial and Special Education*. 35(2), 114-122.

Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry,* 71(2), 257-261. https://doi.org/10.1037/0002-9432.71.2.257

Soke, G. N., Maenner, M. J., Christensen, D., Kurzius-Spencer, M., Schieve, L. A. (2018). Prevalence of co-occurring medical and behavioral conditions/symptoms among 4-and 8-year-old children with autism spectrum disorder in selected areas of the united states in 2010. *Journal of Autism and Developmental Disorders.* 48(8), 2663-2676.

Stratis, E. A. & Lecavalier, L. (2015). Informant agreement for youth with autism spectrum disorder or intellectual disability: A meta-analysis. *Journal of Autism and Developmental Disorder,* 45(4), 1026-1041.

Stuart, M. & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders.* 3(1), 86-97. https://doi.org/10.1016/j.rasd.2008.04.006

United States Census Bureau. (2018). Population Estimates Program, Quick Facts. Retrieved from https://www.census.gov/quickfacts/fact/table/US/PST045218#PST045218

Vogan, V., Lake, J. K., Weiss, J. A., & Lunsky, Y. (2014) Factors associated with caregiver burden among parents of individuals with ASD: Differences across intellectual functioning. *Family Relations, 63,* 554-567.

Vuorenmaa, M., Perala, M. L., Halme, N., Kaunonen, M., & Astedt-Kurki, P. (2016). Associations between family characteristics and parental empowerment in family, family service situations and the family service system. *Child: Care, Health, and Development.* 42(1), 25 - 35.

Weber, J. G. (2011). The ABCX formula and the double ABCX model, *Individual and Family Stress & Crisis.* (pp. 82-96). Washington, DC: Sage.

Weiss, J. A., Sullivan, A., & Diamond, T. (2003). Parent stress and adaptive functioning of individuals with developmental disabilities. *Journal on Developmental Disabilities.* 10(1), 129-136.

Weiss, J. A., MacMullin, J. A. & Lunsky, Y. (2015). Empowerment and parental gain as mediators and moderators of distress in mothers of children with autism spectrum disorders. *Journal of Child and Family Studies,* 24(7), 2038-2045.

Weitlauf, A. S., Gotham, K. O., Vehorn, A. C., & Warren, Z. E. (2014). Brief report: DSM-5 "levels of support:" A comment on discrepant conceptualizations of severity in ASD. *Journal of Autism and Developmental Disorders,* 44(2), 471-476. doi: 10.1007/s10803-013-1882-z

Wendling, B.J., Schrank, F.A., & Schmitt, A.J. (2007). *Educational Interventions Related to the Woodcock-Johnson III Tests of Achievement* (Assessment Service Bulletin No. 8). Rolling Meadows, IL: Riverside Publishing.

White, T., Regan, T., Williams, K., & Klinger, M. (2016). Characteristics of autism spectrum disorder across time: comparing cohorts of birth date and time of assessment. Symposium presented at The International Society for Autism Research Press Conference; Baltimore, Maryland.

Zarit, S. H., Reever, K. E., Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist,* 20(6), 649-655. https://doi.org/10.1093/geront/20.6.649

Zarit, S. H., Orr, N. K. & Zarit, J. M. (1985). The hidden victims of Alzheimer's disease: Families under stress. New York, NY: New York University Press.

Zarit SH, Orr NK, Zarit JM. 1985. The hidden victims of Alzheimer's disease: families under stress. New York: New York University Pr.

Zarit SH, Reever KE, Bach-Peterson J. 1980. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist, 20:649–5

Zimmerman, M.A. (1995). Psychological empowerment: Issues and illustrations. *American Journal of Community Psychology.* 23, 583-599.